Towards a Conceptual Process-Oriented Framework for Patient-Centered E-health – An Exploratory Study of Current Projects in Sweden

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Abstract

This paper provides an overview of e-health and patient-centered care (PCC) from the perspective of one county council in Sweden, with a focus on chronic sickness. The aim is to suggest a framework for working with integrated IS/IT in support of PCC projects. Literature from several areas is reviewed, including PCC, chronic sickness and process-oriented health care. Experiences from a number of projects are presented, with a focus on the current use of IS/IT support. The experiences are clustered under a number of themes, providing outlines of a model for planning IS/IT in PCC. The paper ends with a discussion of challenges of using IS/IT for PCC in the area of chronic care, based on the proposed framework.

Keywords: Patient centered care, E-Health, IS/IT planning, chronic health care.

1. INTRODUCTION

Increasingly, health policy makers in Europe have acknowledged the potential benefits of e-health [1], one main political aim being to foster patient empowerment. There are a great number of studies of different initiatives and pilot projects, which, however, only focus on one side of the interaction between the healthcare system and patients, or on just one specific condition, illness or situation. In this article we will argue that there is a need for a framework that gives an overall picture of the field.

A focus on patients (i.e. patient-centered care, PCC) and their use of information technology (i.e. e-health) is a clear current trend in the field of health care. Both PCC and e-health areas have had problems that merit a further development of models and framework to guide the development and implementation of solutions. Dubé [2], for example, argues against a simplistic view of patients as rational information users, which is typical of PCC, indicating a more realistic understanding of how patients function when seeking, understanding and using information. Problems concerning the use of e-health are also discussed, for example by del Hoyo-Barolla et al. [3], where the authors also argue for a better understanding of the patient situation in order to get better results from e-health applications.

The basic approach here is to align IS/IT goals with general organizational goals (cf.[4]). It is getting the organization IS/IT connection right, which is the great challenge for success in using IT. This is also noted in the e-health area. Gartner [1] finds that many areas are common to every organization, as can be expected, the list including for example:

*Complexity, i.e. many factors and interrelated dependencies that influence the outcome of e-health projects, for example, the technical infrastructure or the information content.

*Governance, connecting e-health goals with general organizational goals.

*Stakeholder engagement, the involvement of different groups like users, managers, medical experts or IT personnel.

This paper aims to broaden the understanding about how to frame the integration of information systems and information technology (IS/IT) to accomplish and enable patient-centered care (PCC). To limit the scope of the problem area we focus on the field of chronic sickness, and the problems connected to the use of e-health and PCC ideas. The paper is outlined as follows: first a literature background covering the areas of PCC and chronic care. Then we look at a number of current cases, project descriptions in the PCC / e-health area. The paper concludes with a first outline of a PCC / e-health model for IS/IT planning.

2. BACKGROUND THEORY

As a starting point for this research, a number of existing works have been reviewed, including a chronic care model (CCM), a process-oriented care model, and patient centered care (PCC).

2.1 The chronic care model and IT

The paper focuses on patients with chronic conditions, because they have continued interaction with health care providers and need in many instances to handle their own care in their regular life situations. Typical examples of chronic conditions are hypertension, congestive heart failure, depression and diabetes. Wagner et al. [5] present a model for making chronic health care successful. Here, the driving force is identified as a need of a better match between the needs of patients and what the care systems deliver. Behind these problems there are those identified both in the delivery systems and among the patient groups. Troubles with the use of information systems and passive patients are examples of such problems. Suggestions for improving this problematic situation are formulated as the Chronic Care Model (CCM), see Figure 1. The framework has been used by more than a 100 health organizations as a guide for improving quality.

The framework is made up of 6 types of interventions:

1. Health care organizations involve changes on the higher organizational levels of health care. For example, higher-level leadership has proven to be an essential component in the CCM model. This could for example manifest itself in changes in high-level plans and goals.

2. Community support helps to activate and inform patients and families on how to better cope with the challenges of living with and treating chronic sickness. Traditional didactic approaches that provide more knowledge to patients have not proven effective in changing patient behavior. The family and other people close to the patient are important as motivators. Important aspects of behavioral management problems include goal-setting, identifying barriers, and planning for reaching the goals.

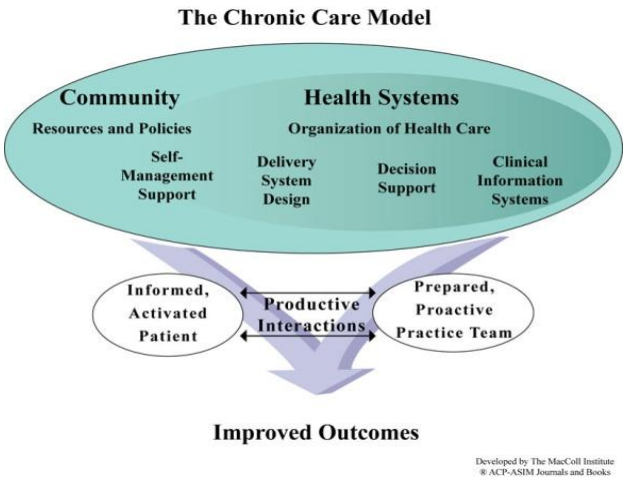


Figure 1. The chronic care model, [6]**.**

3. Self-management support. Guidelines are a common tool for supporting self-management. These are used for increasing the skills required of the patient for managing their condition. Guidelines must be accompanied by a number of other activities including education, reminders, specialist involvement and, as noted above, motivational support from the patient community.

4. Delivery system design involves changes in clinical personnel and patient flows, for example by creating coordination between different categories of caregivers.

5. Decision support includes activities aimed at providing the knowledge and skills of providers. Examples of support are guidelines and patient assessment tools that are combined with recommendations for treatment.

6. Clinical information systems regard the use of technology for collecting, summarizing and reviewing patient data in support of the care process. Here we find the traditional values of information systems, including timely, secure and relevant data about patients and groups of patients. This type of system could be used for calling in patients, planning and delivering care, receiving feedback and reminding patients.

2.2 Patient-centered care and e-health

Patient-centered care has been an emerging approach, in contrast to the 'biomedical model', and a great deal of hope has been attached to this approach when it comes to lower costs and delivering a better quality of care [7]. To empower patients or relatives and make them more active in their own care situation is the main focus in patient-centered care. Being emergent, no final definition has been laid down; it could rather be seen as a collection of ways of making patients and their relatives more active in the health care process. An attempt [8] to capture the area is to see it as a conceptual framework consisting of four dimensions: 'the patient-as-person'; sharing power and responsibility; therapeutic alliance; and 'the doctor-as-person'.

The approach has been criticized for focusing too narrowly on the relationship between the physician and the patient. Then the concept of self-management has been used to broaden the patient's activity level (cf. [9]). The focus turns from the communication skills of the physician towards targeting patient competence as a self-manager [10]. Supporting self-management [11] is one way of approaching this problem. Coleman and Newton [11] argue that self-management is a key component of effective chronic illness care. Self-management includes patient ability in problem-solving and the application of knowledge in real-life situations.

The focus is now on information technology, or more specifically e-health solutions for accomplishing patient-centered care, important characteristics of the development being that IT is designed and used with an emphasis on the patient and on making the patient empowered and active [12]. Patient focus means understanding the patients' needs and preferences in relation to a health care situation. There has to be a focus on the relationship and how to contribute to productive interactions between patients and their health care providers as a whole over time and on the need for patient changes. For e-health solutions this means that the patient and the relatives are seen as much as users and contributors to information provision in the decision-making process as the health care providers (cf. [12]).

This approach takes the view of the patient as a self-manager, but also points out the importance of focusing on the interaction between the patient and the caregivers. In order to understand how IT can provide good support for the interaction as well as for self-management, the caregivers' perspective, 'the other side', also needs to be incorporated in a model.

In a report made by the Gartner group on behalf of the Swedish government [1] a number of problems and possibilities with e-health are discussed. The report evaluates the connection between IS/IT applications and a number of political goals for health care. Of special interest for this study is the "Empowerment" goal, referring to the degree of patient involvement in the care process ([1], p. 23), which lies at the heart of any PCC project. Here we find a number of connections between IS/IT systems and documented benefits. The use of patient portals has given patients a better control of how to contact the caregiver, as measured by the increase of e-visits and decrease of in-person visits to the caregiver. Further, the uses of electronic medical records have contributed to increasing the number of patients with self-management goals. However, on the whole, relatively few connections between empowerment and e-health could be detected, and the evidence seems to be rather anecdotal. Only 2 of 11 types of IS/IT support investigated have had an impact on empowerment. Besides, only 2 measures out of the 37 that were measured were connected to empowerment. Clearly, there are possibilities to further the development and improvement of this area. From a chronic sickness perspective, Gartner ([1], p. 21) presented an interesting figure in the estimate that the use of telemedicine for monitoring could reduce admissions per year throughout Europe by 5.6 million. This is just one figure out of many that could be picked out, but it reminds us about the nature of the problems facing health care, and what potentials there are in IS/IT. But let us first use the knowledge existing in the health care about engaging patients and constructing a framework that tells us about the necessary requirement for making patients empowered to see what role IT can play in that.

3. PROJECT BACKGROUND

The case is based on experiences by one of the authors, who was employed from 2004 to 2007 as project leader at the Development Department at Jönköping County Council in the Southeast Health Care Region in Sweden. The council works in close connection with the Institute for Health Care Improvements in Boston (IHI), Dartmouth Medical School and Clinical Microsystem organization and other organizations working with improvements in health care and learning. The question of supporting and making the care more patient-friendly and patient-centered was always on the agenda in each improvement project. As project leader/evaluator the researcher was involved in health and environment issues for children, the improvement of care for adults with mental illness, tools for changing the life style for elderly healthy people, and different IT projects. The experiences made the shaping of a tentative model for patient-centered care possible with new IT solutions and with the aim to extend knowledge transfer and creation in the relationship between the caregiver organization and care-taking patients. In addition to the projects directly involved in this research, a number of current related projects have also been reviewed in order to broaden the scope of the investigation.

3.1 The strategic process view of the County Council

Process orientation is a solid trend in business development [13]. A number of typical features include cross-functional process connection, focus on the end consumer, how process adds value, as well as measuring and the use of IS/IT in support of these efforts. This has also been used in the health care area, as reported, for example [14]. A practical example of this can be found in [15], see Fig. 2, which reports a case study of a health care organization in Jönköping County in Sweden. Here it is reported that an overall process plan was created for the whole health care organization, and all activities that existed in the organization had to be fitted into this grand schema. The map defines the process roles and how these contribute to the overall mission of the organization.

Maps of this kind have been drawn from the macro level down to the smallest micro-system or front-end ward within the County Council, altogether constituting a rather complex organizational model. Thus, in order to empower patients there is a need for a different view of this health system – the view of the patient.

4. E-HEALTH PROJECTS

In this section we present a number of on-going projects, with a focus on how to create PCC in general and also on using IS/IT as support for that.

4.1 Growing people - supporting parents

The Growingpeople.se website is directed towards parents and contributes on a broad scale to knowledge about children in general, not only about sick children. The site is managed by medical experts in child medicine and is today financed by advertisements and contributions from some of the regions in Sweden. One feature that makes this service successful is its great effort to translate one language into an everyday language that every parent can understand and relate to. This language barrier is a problematic obstacle to helping the parent to understand the child's situation. The material is filtered and organized so that the most plausible understanding of a situation (possible sickness) is focused on, and the more extreme and serious problems are put in the background so as not to alarm people unnecessarily. It is also possible to ask direct questions, which has led to a substantial question database. Today it is estimated that half of Sweden's parents have visited the site. In child care at Jönköping County Council this website has served as a communication tool for physicians and nurses in explaining the evidence-based medicine or experience-based practice to parents. This development and the use of this kind of websites make it possible for patients and relatives to understand their conditions in an everyday language, enabling them be more aware and knowledgeable about the best practice in care right now. By the possibilities to ask questions the parent can also obtain a second opinion and connect to the expert's knowledge in between visits, whenever questions come up. But it is also necessary to offer knowledge about how to cope with a new situation both for the patients and for their relatives. This could be supported in the same way by supplying the connections to others in the same situation on a secure web-portal.

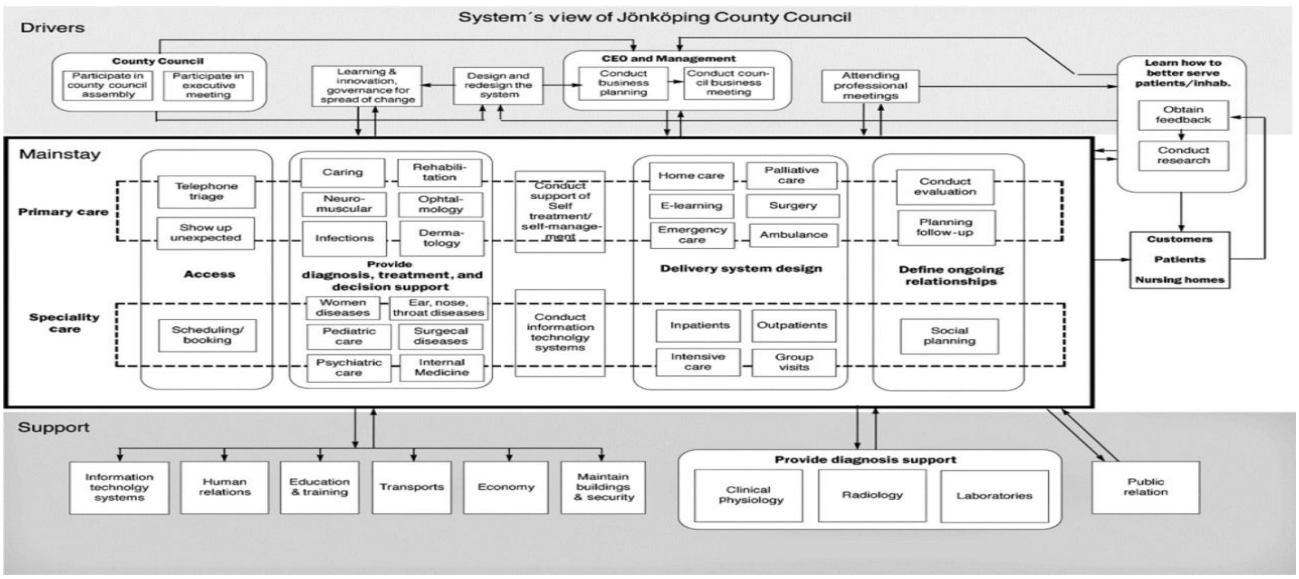


Figure 2. "Map of key processes-systems, Jönköping County Council" [15]

4.2 A support site for young diabetes patients

One site that focuses on the community around the diagnosis (diabetes) is www.diabit.se. The site is sponsored by a Swedish region and aims at helping patients, or rather parents to children with diabetes, to treat the sickness at home. The site contains a wide range of basic facts around diabetes as well as a question and answer section. A major part of the site focuses on the interaction between patients/parents that supports building a community, with a traditional forum for discussion, with rooms for different aspects of diabetes, and on different groups of patients. The forums make room for discussions among patients or parents, where questions or worries can be debated. Most answers come from the community rather than from medical experts. There are also movies that give an insight into the everyday life of diabetes patients. A special focus is on young people with the sickness, who can discuss their situation with other young people. The site also consists of support for registering their own measurements of blood glucose over time (with meters in the market this can also be done all digitally) and for discussing it with nurses or/and physicians to learn about the relationships of medicine, diet and physical activities. Here we can see that the site helps to understand the condition but also makes room for sharing patients' own experience of living with a chronic disease.

4.3 Preventive care for elderly people

One project focused on how elderly people can avoid problems and medical conditions that come with age. In the project, tools for improvement used mainly for organizational projects (cf. [16]) were tested at an individual level. The aim was to make people change their own behavior about home safety, nutrition, exercise and social networks. The project made them aware of the situation at hand, e.g. the risk of falling in the home environment and the well-known consequences of a fall such as a broken leg or arm. They measured near and actual falls and then made improvements like removing thick carpets or electric cords, or putting a towel in the bathtub, which resulted in fewer near and actual falls. Areas like food, exercise, and social life were discussed. With an extended IT support for this kind of projects we see that the approach can be used in other circumstances, helping people to overcome the obstacles in the way of a change in life style. The project ideas and program were spread all over Sweden and the original team members basically educated future advisors, for example in local courses The project is today supported by a website, http://www.lj.se/passionforlivet (meaning: passion for life). Preempting problems is always the best way, the question is how to motivate people to become engaged and want to learn. The project was focused on making this an appreciated event that stimulates and motivates life style changes.

4.4 Care on the web - IT applications for the patients

There has been great focus in the County Council on supporting the internal care processes with IT solutions, but there are still rather few solutions that offer support for the patients. Some small pilot and research projects have been conducted, but for the regular patient and care processes there is limited support. Today it is possible to get a picture of the organization and how to get into contact with it, and some overall regulations as well as some standard care plans are accessible through the website. As a patient you can also cancel your planned visit and get access to the national web pages (www.1177.se) that give general advice and information about symptoms, diseases and care.

The model proposed here is far from supported by applications available today, even though new projects that can support the need of better knowledge transfer and creation are running and starting on different levels in the Swedish health care sector. But there is a need to get an overall picture or model in order to see how the different IT solutions constitute a total delivery of patient-centered care processes. More advanced tools for measurements like digital scales, pedometers, blood pressure tools that transfer data to a web portal along with a diary of nutrition, exercise, self-reported feelings and social contacts are required, where the patient can learn about how different life style changes will improve the conditions caused by the illness.

5. TOWARDS A PROCESS-ORIENTED MODEL FOR IS/IT PLANNING FOR PCC

We can now sum up a number of key activities that might form a basis of an e-health process for patient-centered care. We focus on the different phases that a patient must go through on the path to a healthier life.

5.1 Understanding

In this phase the focus is on the process of how patients create an initial understanding of their illness. The care team can supply the output from evidence-based research in an everyday language and by various means (probably mainly through personal discussions with the patient or through written material). On the other hand, the patient will very probably come into contact with various public sources, typically magazines or www-based information resources – see the discussion about growing people above – like popular science. This phase is about creating a learning process, which in turn creates a foundation of understanding that will make the continued care process possible. This phase is also about making the caregiver understand about the patient understanding of the condition.

5.2 Measuring

Facts must be gathered as a first step towards taking effective action against the sickness or the symptoms of the condition. In a traditional world this usually means that the caregiver provides this within the health system organization. In a patient-centered world we would expect patients having (on loan maybe) their own instruments, and in the best case the information is captured, stored and made available to the caregiver, such as blood glucose testing for diabetes patients. This can also include screening, questionnaires where the patient enters answers to different questions, making observations and so forth. This is primarily used after the patient has gotten an evaluation and been diagnosed by the care team, to follow up or adjust treatments.

5.3 Decision-making

Traditionally, the caregiver decides and gives "orders" to the patient – the 'biomedical model'. In the patient-centered world of patient empowerment, the patient should be active and take responsibility for the choices of care. The idea of shared decision-making [17] is a key to engagement and compliance with care. At the same time the patient must have the right support and understanding, since, for example, the generation of options is not something the patient can achieve without proper support. The support lies in the compilation of facts and

measurements and the formulation of action plans that are in line with the patient's need.

5.4 Care planning

The planning is important for successful action, and in health care there are standard care plans for many different conditions. Here we find support like scheduling, instructions for how to act or reminder systems. Planning, as a process preparing for action, does not receive very much explicit attention. Transforming decisions made into action largely concerns understanding the patient life situation and removing barriers to action. An important step can be adjusting standard plans towards individual ones. In the end the "shared" part is the central one, i.e. the essential step in the interaction between patient and caregiver, whereas planning is unnecessary unless the patients and/or their relatives understand and agree to the plan when they are at home.

5.5 Action

Here the focus is on how to support patients in taking action in their own care plan. Many chronic conditions require life style changes for the patients in order to reduce symptoms – stopping smoking, diets, physical activities, security at home, etc. One problem is when activities that the patient wants to change are not carried out. A great deal of this relies on the motivation of the patient, since the action must be seen as important and meaningful and show quick results – self-improvement tools can be helpful to make the proper action happen, like in the case above with elderly people.

5.6 Writing records

The health care systems are largely concerned with gathering and storing facts that are generated throughout the care process. These systems are present during the entire process. Looking back at the Gartner report [1], we can see that many of the IS/IT systems are of this kind. The list includes for example: electronic medical records (EMR), computer-based patient records (CPR), and electronic health records. In the IS/IT tradition a great deal of data is gathered; however, the question that needs to be asked is to what extent a PPC approach to health care actually constitutes support. The lack of patients' own records of data in these systems makes it impossible for a care team to learn about the individual patient's care process. This will be essential and can contribute to better communication between patient and care team – where the actual care activities at home can be visible rather than the planned standard care provided by the team.

6. CONCLUSIONS

The aim of this paper has been to work towards a process-oriented PCC model for e-health. The work has been based on three theory areas: PCC, CCM, and process-oriented care, and has been further informed and directed by the use of several current e-health projects. As a concluding discussion we can make some final comparisons with the ideas from the background framework.

- Comparing with CCM. We have clearly seen the need of a holistic view of the care process, since it is complex and many aspects have to be put on the map. What has been added to this perspective is a clearer focus on the two sides of the process, i.e. the patient side and the care team side, and on the need to plan for how these interactions should be structured. The focus on IS/IT has been made more prominent.

- Looking back on the care process map that was reviewed, a clear change in perspective can be seen. The map [15] uses a process based on four major steps: assessment, diagnosis/decision-making, delivery system and ongoing relationship. The last stage refers to a long-term relationship, the follow-up to the care given. That process has more of a health care organization perspective, not one that has the patient in focus.

- The IS/IT planning perspective of the model is on a rather high or strategic level, following traditions of ends-means analyses based on normative descriptions of processes. The idea is that if we have an ideal view of how things should work and can describe the current situation, then we can make a gap analysis and suggest changes. In this case this means a list of IS/IT artifacts that should be implemented in order to create or support certain activities within the health care process.

There should also be room for some critical reflections on the proposed process model. The model might appear as a rather rational and linear view of the care process, and this might not always be the best way of understanding care in practice. The phases should be understood as the set of activities that should be tackled during the process, how they appear in time and how the interaction in time might become much more complicated. A future direction for research would be to further explore and give practical examples of how care processes can be guided and planned by the use of the model. In such examples it would be possible to go into the complexity of getting everything in place and how to resolve practical and time constraints between activities within and in between phases. The process orientation should in principle mean that all measures within the health process should relate to the increased value of the patient. This aspect is right now covered in the interaction dimension of the model. However, this is an aspect that would benefit from more work, especially on the measurement of patient values.

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