Patient-Centered Care as a Learning Process

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Abstract. The focus of this paper consists of investigations into a strategic planning framework for information systems in support of patient-centered care (PCC) processes. The planning perspective that underpins the research includes learning theories, organizational learning and knowledge management in general. A brief review of current PCC goals and perspectives is used as a starting point for an investigation of PCC activities and support system. The examples of PCC activities are organized as a learning process and presented in a framework.

Keywords: Patient learning, Information systems, Planning framework, E-health.

1 Introduction

Patient-centered care (PCC) is an emerging approach to health care, on which a great deal of hope has been pinned as it indicates lower costs and better care quality (Laine and Davidoff, 1996). PCC is a break in a traditional disease-oriented model of care (Epstein, 2007). However, a coherent definition of PCC is still to appear, one recent effort being given by Robinson et al. (2008, p. 600) according to which "fundamental characteristics of PCC" include ”a) patient involvement in care and b) the individualization of patient care”. In the center of this definition lies the interaction between patient and caregiver in the hope of a better quality of care, increased patient satisfaction and higher patient adherence (Robinson, et al. 2008, p. 601). This makes PCC an approach for how to design and perform health care which contains implications for every aspect of the health care process. In this paper we focus on how information systems and information technology (IS/IT) could be used to support a PCC strategy towards health care. Our approach is to build on a learning tradition within IS/IT and to apply this to the task of planning and designing IS/IT support for PCC activities and processes. The contribution of this paper is a literature review that focuses on the connection between pressing PCC issues and current theoretical frameworks, concept and models. The study evolves into an outline of knowledge- and learning-oriented planning and design framework for PCC support.

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2 Background: Patient-Centered Care (PCC)

A number of possible aspects of the concept of patient-centered care (PCC) have been identified. A fairly early expression of patient-centered care was made by Sherer et al. (1993), who defined it as a "[d]esign of patient care wherein institutional resources and personnel are organized around patients rather than around specialized departments". This can be seen as an organizational approach to achieving patient-centered care. From economic aspects a number of benefits would be accrue from a patient-centered approach. Charmel and Frampton (2008) argue that a there is a solid business case for PCC, with great possibilities for lower costs as well as for an increased market share. Robinson et al. (2008) adopt four PCC perspectives on: 1) The public policy perspective, focusing on the partnership among practitioners, patients and their relatives, and on the care decisions that are made, so that these decisions follow the needs and wants of the patient and enable the patient to take part in these decisions in an informed and knowledgeable way. 2) The economic perspective, which focuses on patients as consumers of health care and on their competence to make informed decisions with respect to various quality characteristics of the care. Robinson et al. 2008 mention as one example the possibility of direct-to-consumer marketing of pharmaceuticals, and how this connects to the patient as decision-maker involved in care decisions. 3) A clinical practice perspective, focusing on the view of the caregiver and on the changes in how, for example, practitioners understand, interact with and treat their patients. The PCC approach affects how the caregiver understands patient needs and tailors the care to be given as well as generally increasing the humaneness of the care. 4) The patient's perspective, finally, focuses on patient priorities, which might include factors like respect, courtesy, competence, efficiency, decision-making, time for care, availability, accessibility, wants/needs of care and communication/information. To handle the complexity of PCC models have been developed of what could be included in a PCC care process. Steward et al. (1995) propose a model of six interacting components: 1) exploration of the illness/disease and the patient's experience of it, 2) understanding the patient as a whole person, 3) planning care, goals of treatment and areas of responsibilities, 4) work with prevention and health promotion, 5) creating in the patient-doctor relation a working therapeutic relationship including power sharing, and 6) a realistic and effective use of time and money. Building on this model, Aita et al. (2005) suggest a somewhat generalized and more concise one for PCC. This model contains four components: 1) the physician perspective, including style, value or medicine philosophy, 2) the patient perspective, including priorities, values and the philosophy of health, 3) practice organization, including priorities and culture, and 4) the community aspect, including culture and priorities.

3 Investigations of a Patient-Centered Care Model

3.1 The Condition for Understanding - What Is Knowledge

The focus in support of care processes is often on fact, information and messages that are directed towards the patient. The move towards learning/knowledge puts the focus on what happens with the facts when they have reached the patient, and on what it takes for facts to become actions. In the core of this we find the concept of knowledge and the processes that surround it, like creation, storage, transfer, use and so on, in short, what a patient understands from the facts presented. This is a process going on in all the aspects, including measures, planning, choices, actions and evaluations. Forbat et al. (2009) discuss the nature of PCC and its key feature of patient involvement in the care process, which means that the patient is part of planning, decision-making, delivery and evaluation. However, this involvement is not enough, but the patient must really be engaged in the care process. This requires that the patient gains a personal understanding of the sickness, and this does not mean just an information-seeking process. Forbat et al. (2009) argue that patient and care personnel must be coached into being able to be engaged. The method which Forbat et al. (2009) suggest builds on study groups of patients and staff that work according to a Plan Do Study Act (PDSA) method as a support for learning and building personal understanding.

3.2 Measuring – Gathering Facts

Gathering facts by taking measurements on the patient is central for making plans and decisions about the continued care process. In PCC this has been translated into a need of personalized measurements that capture the individual perspective, or, how the patient perceives his or her situation. The outcome of a measurement might be different whether a patient or a physician makes the assessment (for example, Stephens, 1997). In the care of chronic illness special measures for understanding the long term progress of the individual have been developed. The typical example of this is the “quality of life” (QoL) concept. Davidson et al. (2004), researchers on heart failure, argue for the task of assessing patient needs as being central to tailoring the care for the individual patient. The approach builds on structured measures to capture this information, including for example patient satisfaction, quality of life and utility. But the key is how to individualize these measures, by involving the patient and making him or her take active part in the measurements, and turning it into a long-term process and not a one-time happening. In their paper the authors argue for a general framework and for developing specific and quantitative needs assessment questionnaires within each area. They also point towards a number of problems with the QoL measure. First, this concept is not properly defined, which makes it somewhat less reliable even though it often includes factors like physical functions, psychological processes, social and economic concerns, and spiritual/existential aspects.

3.3 Planning – Exploring Options for Care

A great deal of what precedes the actual decision and execution of individual care could of course be seen as care planning. From a decision theory aspect the planning phase is about generating options which are to be decided on later. An example of this could be found in a study of a goal-setting support for diabetes patients (Langford et al., 2007). In this case a framework for a self-management goal cycle has been set as support for the patients. The central activities include: 1) visits, both personal and group meetings, also including scheduled or ad hoc telephone calls; 2) goal lists, i.e. lists of things the patient should achieve; 3) measurements, including one measure for the likelihood of reaching a goal and one for measuring the ability of the caregiver to solve problems associated with the goal; 4) a checklist for the caregiver as support when gathering facts about the situation; and 5) problem-solving activities when a problem arises about the goal.

3.4 Decision-Making – Making Care Choices

The decision on what care a patient needs is the centerpiece of the care process. A patient who is well informed and is thus empowered to participate actively in the decision plays an important part in a patient-centered care model. The preceding activities build up to this moment, the patient-doctor meeting, facts and measures, the planning and the learning processes all supporting an empowered patient. Great advantages are expected from a patient-centered decision including a focus on issues that are important to the patient, decisions made in line with patient values, the improvement of patient compliance with and commitment to the care. In the long run this would also mean a lower total cost for care. Shared decision-making is a concept advocated in a brief case study (Walker, 2008) as part of a patient-centered care model. Walker (2008) defines shared decision-making as "[t]he collaboration between patients and caregivers to choose treatment options in line with patient health plans". The patient in the case becomes informed by support like counseling for good information gathering and understanding, videos with treatment choices and facts in form of a treatment handbook. Gustavsson et al. (1999) present a study of a support system that was provided to a group of patients for home use. The patients were provided with support like information, decision support, and connections to experts and other patients. The impact of the system was measured with self-reports of their quality of life and of the frequency and duration of their use of medical services. The benefits included, for instance, patients spending less time during care visits, communicating with health providers by phone and experiencing fewer and shorter hospitalizations.

3.5 Action and Learning: Connecting the Cause and Effect of Self Care

Taking the action that is the actual care is of course the goal of the care process. The actions can be taken by patients more or less on their own, or be performed by someone else, maybe a caregiver from the professional organization, or by someone close to the patient. The focus of PCC is to empower the patient to be able to perform self-care. Robinson et al. (2008) study PCC from an adherence perspective, defining the concept as the patient's efforts to follow health care advice. Adherence is related to the concept of compliance, defined in Robinson et al. (2008) as a when a person's behavior coincides with clinical advice. To use the term adherence reflects more of PCC, i.e. individual care and patient involvement. Self-management is one approach to creating patient-centered care. Coleman and Newton (2005) discuss self-management in the context of chronic care, including a number of aspects: 1) Patient education and application in real time situations. 2) Providing the patient with problem-solving skills. 3) Helping the patient to act with efficacy, using the most appropriate alternatives. 4) Training the patient in recognizing barriers to action and how to remove these. 5) Performing motivational interviews to support patients to commit themselves to the care. However, self-management does not work on its own; it requires that the other aspects of the care process are in line. The patient must be able to understand the sickness with its social as well as physical consequences, do measurements, obtain help with goal-setting and perform follow-up and evaluation. The care process must be integrated with a focus on the patient's ability to enact the care. Instructions like drug warning labels form one possible type of support for self-care, but making instructions into effective tools for learning and acting is not simple. Webb et al. (2008) give an example of a warning text for prescription drugs. The findings from a discussion group show that a majority of the participants found that the texts contained difficult language or were confusing. The participants in the study requested more actionable texts in the most simple and concise manner possible. Webb et al. (2008) argue that the level of misunderstandings among patients with regard to warning texts is high, and that such texts should be developed towards adopting a patient perspective.

3.6 Keeping Records: Documentation and Evaluation

Evaluation is needed to ensure that PPC approaches promote better health for patients. Building the databases needed as sources of facts is closely related to record-keeping. Both evaluation and records are ongoing activities that are performed in each phase of the care process, as discussed throughout this section.

Evaluations are necessary for making a good case for PCC. For example, Stewart et al. (2000) made a study of the differences in outcome between cases using and those not using a patient-centered approach. The outcome of this study showed that patient-centered communication influences patients' health because they perceived that their visit was patient-centered. Stewart et al. (2000) therefore drew the conclusion that patient-centered practice improved health status and increased the efficiency of care by reducing diagnostic rests and referrals. For the patient to find common ground with the physician was especially important. Cassivi et al. (2008) discuss the problems with measuring by giving an example of a framework in the thoracic surgical area. The main problem is identified as what is called a void in quality measures. The problem is one of a duality in the use of measures. The measures are both used for quality improvement or for economic aspects of care and, together with these, as means for supporting the right care choices. This is also reflected in the type of measures, whether they are outcome-oriented or process-oriented. To fill this void in measures, frameworks for measuring and measures should be developed on the basis of a patient-centered view. Cassivi et al. (2008), also point toward the need of building databases of records from the measures and the importance of these records for future quality improvements. The financial outcome is also connected with the evaluation and measurement of PCC and its importance for care institutions. Charmel and Frampton (2008) point to number of economic reasons for PCC, including reduced length of stay, a lower cost per case, fewer adverse events, higher employee retention rates, a decrease in malpractice claims and increased market shares.

3.7 Interactions: The Patient-Doctor Meeting

In the communication processes the exchange between patient and doctor is the key piece, which has received a fair amount of attention from several perspectives on the PCC area. This activity is not entirely comparable to the other six above. The patient-doctor contact is a meeting that in practice is the time and place where many of the other activities take place. However, what we here focus on is the nature and condition of the interactions between patient and doctor as such. The nature of this interaction is a key to patient learning in the sense that it is in the presence and interaction with another person (i.e. the doctor) that a fact becomes trustworthy and real to the patient. In this sense it is a central aspect of the process of patient learning. Culture-competent communication has been discussed as one aspect of the patient-doctor meeting. One example of a frame for these processes is the cultural awareness model, a model suggested by Teal and Street (2009) consisting of four elements: communication repertoire, situational awareness, adaptability, and core cultural issues. These four elements indicate a set of skills that the caregiver should possess, and which could form an area for learning and KM activities. It would probably be even more to the point to have support systems for the caregivers in the current situation and as support for learning over time. Another example comes from cancer care, where Epstein and Street (2007) present a model for patient-centered communication. This model consists of six interconnected functions: fostering healing relationships, exchanging information, responding to emotions, making decisions, managing uncertainty, and enabling patient self-management. The book argues for the connection between good communication and the outcome of the care given.

4 Conclusion: PCC as Learning Process

The aim of this paper has been to investigate how to understand and model a health care process as a patient learning process for the use as a IS/IT planning approach. Starting with a tentative model of PCC, we have investigated current practices of PCC as reported in the literature, and found the model a useful way of understanding the PCC process. All the seven types of activity are in use today, albeit not in a coherent or systemic way. The focus of most of the activities is not on the learning aspect as such, however important part it is. Most of the practices can be seen to deal with more than one type, but they usually have a focus on one of them. There are clear needs of development in all these learning processes, and the way they interact over time, all directed towards an integrated and systemic understanding of this problem area. For the care organization learning process there has been progress in directions like care improvement research, but more generally it would be expected that lessons could be learnt from organizational learning areas. When it comes to community learning, which takes place on a person-to-person level theories within the social learning area could be expected to contribute. The picture of the patient learning process seems to be a very information-oriented and rational one. This is the picture that emerges both in the practice as we have studied it and in the different situations that we have reviewed in this paper. This sits well in the planning perspective and a rational world view of information systems in general. However, this may not be the best way of understanding how a patient really experiences the process.

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