Computer Support for Shared Care of Diabetes: Findings from a Danish Case

Keld BODKER1, Maren Fich GRANLIEN
Computer Science, Roskilde University, Denmark

Abstract. Shared care has been announced as an effective model for care of chronic diseases. In the paper we discuss various facets of IT support for shared care of diabetes. Based on an empirical study of a project in Denmark we identify various challenges involved with IT support of shared care; structural problems and lack of attention to general practitioners' practice and to clarify the meaning of shared care in the actual project. We propose the importance of reaching agreement as to what is shared and we suggest a distinction between two levels of shared care: an epidemiological level where hospital specialists and national authorities need to monitor the disease based on data from the general practice; and a operational, daily level where the professionals dealing with an individual patient and the patient share information to help the patient deal with his/her situation on a everyday basis.

Keywords. Disease mgt, Communication, Strategic plans, shared care, diabetes

Introduction

Chronic diseases are affecting a growing numbers of patients, and dealing with these diseases is imposing growing costs to the healthcare budgets in western countries. Despite the substantial resources allocated to healthcare, there is a general and growing dissatisfaction with the apparent lack of coordination, continuity and support in the care of individual patients. This is particularly the case when treatment involves several healthcare providers, i.e. hospital departments, outpatient clinics, homecare providers and GPs, which is the case with chronic diseases. On this background shared care has been introduced as a concept and general idea to improve the quality and efficiency of complex care services involving the combined efforts of a variety of healthcare agencies and professionals. Shared care can be defined in the following way: "Shared care applies when the responsibility for the healthcare of the patient is shared between individuals or teams who are part of separate organizations, or where substantial organizational boundaries exist" [1]. Other authors define the concept differently, but we find this definition to capture the overall ideas quite well; however it is also clear that the definition is quite vague and needs to be operationalized for specific programs.

1 Corresponding author: Keld Bodker, Roskilde University, bldg. 42.2, Universitetvej 1, DK-4000 Roskilde, Denmark. E-mail: keldb@ruc.dk
Shared care programs focus on improving coordination, collaboration and knowledge sharing among healthcare professionals as well as involving patients as active participants in these processes. Research has shown that shared care programs can improve the quality and efficiency of care significantly [2], but also that the implementation of such programs is a long-term and difficult process [3-5]. In Denmark, IT-supported shared care is a central part of the national IT strategy and the action plan with regards to the national initiatives concerning diabetes [4].

The aim of the paper is to discuss the concept of shared care in relation to dealing with diabetes treatment, and in particular to illustrate the challenges involved in designing computer support for shared care. We draw upon an empirical study of a Danish project to discuss some of the important challenges involved in such projects.

1. Case Study and Methods

A case study of the implementation of SharedDiabetes is the empirical basis for our discussion of challenges involved in providing computer support for shared care in diabetes treatment. The system was developed and implemented in the central part of one of the five Danish regions and is now being spread to the rest of the region - from now on referred to as Region A. The system is being promoted as a system for supporting shared care of diabetes, i.e. containing data and functionality relevant for the treatment of patients with diabetes. The system is a web-based application working independently of the other systems of the care providers with only little exchange of data. The system is integrated with the laboratory system used in the region's hospitals, while integration with the GPs' electronic patient record systems is based on EDIFACT messages to the GPs' systems. At the time of our investigation the outpatient clinics did not have an electronic patient record and used SharedDiabetes as their main system for diabetic patients together with the hospital patient administration and medication system. SharedDiabetes is used by all outpatient clinics, a substantial part of the GPs, and has recently been made accessible to patients through the Danish National Public Healthcare Portal (sundhed.dk).

SharedDiabetes was developed in response to an action plan for diabetes from the Danish National Board of Health in 1994 [6]. Following this plan, a regional diabetes committee was established, diabetes outpatient clinics were restructured to reflect a team oriented care, and a need for an IT system that could help monitor and support the treatment as well as provide a means for quality assurance was identified. The regional diabetes committee established a project with a large pharmaceutical company that had a system under development. Later the development of the system passed to a large IT company. The project involved representatives from the various stakeholder groups, e.g. diabetes doctors and nurses from the outpatient clinics and GPs, mainly two diabetes practice consultants i.e. GPs who - beside their consultation - work with improving the collaboration between diabetes outpatient clinics and general practice. To understand the many stakeholders it is necessary to understand the treatment of diabetes in Denmark.

When a suspicion for diabetes with a patient is discovered - at a hospital or in the GPs practice - the patient is referred to the diabetes outpatient clinic to have the diabetes diagnosed properly. Here the patient upon diagnosis receives initial treatment

\[2\] a pseudonym.
with the goal of becoming well regulated, i.e. achieve a stable situation by a combination of medication, a changed diet and physical exercise. In the outpatient clinic the patient is treated by a multi-disciplinary group of specialists: diabetes doctors and nurses, dieticians, ophthalmologists (eye specialists), and podiatrists (feet specialists).

When the patient is well regulated, typically within less than a year, the patient is discharged to his/her GP. This is the workflow for type 2 diabetes - by far the most widespread (type 1 patients are treated in the hospitals). Upon discharge, type 2 patients are seen in the GP on a regular basis, every three months and a more thorough control every 12 months. Once a year the GP refers the patient to see an eye specialist and a foot clinic. The GP evaluates indications from these specialists as part of the annual status. Late complications of diabetes are serious to the individual patient and costly to deal with for the healthcare system. Effective care and the patient's active participation are central to reduce the late complications, and thereby improve the quality of life for the patients and lower the costs for society.

The empirical investigation took place throughout 2006 and comprised a series of interviews, observations and document analyses. Interviews were semi-structured and lasted 45-75 minutes; they were recorded and later transcribed. In region A, three GPs were interviewed about shared care (referred to as GP1, GP2, GP3). In addition to the interview, we conducted a think-aloud test with the GPs where they went through the system on the basis of a short consultation scenario. Further, two persons from the IT company and one from the regional committee were interviewed. Observations at an outpatient clinic were carried out over three days - in total approximately 15 hours of observation was documented by field notes. Interview transcripts and field notes from the observations were analyzed using a coding process inspired by the theoretic sampling technique known from grounded theory [7].

2. Results and Discussion

The project in Region A was well integrated with the regional activities of diabetes treatment, as evidenced by [6] and our interviews; the system is actually quite well designed and technically sound; and a leading medical doctor from the regional University Hospital has recently claimed remarkable results in terms of significantly less late complications to the shared care initiatives (TV2 News, May 15, 2007). However, findings from the study also point to a number of challenges for IT supported shared care, especially related to GPs’ use of SharedDiabetes. Some of these challenges are related to structural issues, some are related to the insufficient involvement of key actors and some are related to our central questions of what is shared or what should be shared.

2.1. Structural problems and lack of attention to general practitioners' practice

A large part of the structural problems comes down to the fact that GPs are private businesses while diabetes outpatient clinics are part of public hospitals. In Denmark virtually all GPs have electronic patient records, and there are more than 20 different EPR systems in use in GP's clinics. Currently the Danish regions owning the public hospitals are developing and implementing full-scale hospital EPR systems, but when the SharedDiabetes project started, and when the system was first implemented in the
region, there was no EPR system at the region’s hospitals. For that reason SharedDiabetes was designed for use as the main system for diabetes patients, in the outpatient clinics as well as in the GPs.

The GPs, however, have their own EPR system as their main system. This means that the use of SharedDiabetes in GPs' clinics is on top of their EPR system involving extra work and overhead. When seeing a diabetes patient the GP has to log into SharedDiabetes by opening a browser window, check data from previous consultations, register the relevant data from the current consultation, and then return to the EPR system. This extra work was actually acknowledged. As part of the project the services to be performed by GPs were regulated and included in the financial agreements between the GPs and the region. However, in the daily use the lacking integration causes frustrations, as illustrated by the following quote. "I was quite insisting on this matter, but it was technically not possible to do this at this point in time. I am of the opinion that a [shared care system] should have been developed where the application should be within our computers" (GP3). As noted by the GP, achieving a tight, or seamless, integration between SharedDiabetes and his EPR system requires a vast amount of resources. Given the software architecture decisions in the project this would involve all the 20+ providers of EPR systems for GPs.

In general the GPs find that SharedDiabetes does not support their way of working. The system is designed for use during the consultation to facilitate involvement of the patient (to help the patient become active in his/her own treatment). This is how we observed the system being used at the outpatient clinics. However, the GPs we interviewed never used the system during a consultation but preferred to consult the system before and register the data after the consultation. "I would rather use the time – and I might sound a little self-righteous now – but I prefer using my time with the patient and then use the computer either before or after [the consultation]. That’s what I do generally" (GP2).

Due to the fact that the information input to SharedDiabetes is not integrated with the GPs' electronic records, and the fine level of granularity of data requested by the doctors at the outpatient clinics, using the system becomes tedious extra work in the GP clinic. This is reinforced by the relatively low frequency of diabetes patients in the general practice. Less than 5% of a GP’s consultations regard diabetes [8], which means that s/he typically has 50 patients or less with diabetes and only one fourth of them is also being treated by the outpatient clinic. What this means is that using the system never becomes routine, the GP always has to use extra attention - for example to locate a specific field.

These findings resemble experience from other studies of the uptake of clinical information systems, for example [9]. The implication is that by not attending to the GPs' professional practice regarding use of computers in their consultations, risks are high that GPs will only use a shared care system to an extent fulfilling the minimal requirements in agreements between the region and GPs. From this, one could hypothesize that a decreasing number of GPs would use the system as intended. We have not been able to test this hypothesis, as we have only been able to obtain data on the number of GPs having followed a course on SharedDiabetes and hence obtained a password to the system (more than 50% of GP clinics [6]).

Another implication from the findings could be formulated as a question: Could we approach some of the challenges head-on? If, for example SharedDiabetes was extended to include other chronic diseases, how would that affect the uptake in GP? We can of course only speculate in trying to answer such questions. It is clear that this
would address some of the challenges: the GPs would use the system more often and use would thus become more routine, and it would become more feasible to address the question of proper integration with the GPs' EPR systems.

2.2. What does shared care actually mean?

We have illustrated a tension between requirements from the outpatient clinic care providers towards a fine granularity of data in SharedDiabetes and the GPs' wish for simplicity and ease of use. From this, we could easily foresee a situation where diabetes specialists blame GPs for not using the system as intended, while GPs think that the system - with a level of detail of information and mode of interaction based on the outpatient clinics' situation - illustrates the privilege of resources needed to attend to details of care in public hospitals without attending to the practicalities of running a GP clinic. We suggest the tension might be more productively used to understand the conditions and challenges for developing and using shared care applications.

From our analysis we suggest the key is not only to understand what is shared and with whom, but also to reach an agreement on what kind of shared care we want to support. From the perspective of dealing with the individual patient as a diabetic, care may be shared between the primary actors involved, i.e. the GP, the various specialists in the primary sector and home care providers. However from the perspective of the GP it only rarely makes sense to talk about care as shared with the outpatient clinic. This means that the working interpretation of shared care applied in the project, "we talk about shared care when a diabetic has received treatment, or has been registered, in both the outpatient clinic and in the GP within the last three years [6, our translation]", is not anchored across all shareholders, and potentially does not represent all shareholders' view.

From a specialist perspective many data are relevant and valid. The data are needed to support a long-term level or an epidemiological level of shared care where hospital specialists and national authorities need to monitor the disease based on data from the primary sector. However to the GPs, the low frequency of diabetic patients and the mode of interaction with the system come at odds with their professional practice. In our interpretation, they acknowledge a need for support on an operational, daily level where the professionals and the individual patient share information to help the patient deal with his/her situation on an everyday basis. Many GPs state that the system does not contribute any new, and to them, relevant information. It is actually hard to find support for shared care in the treatment of diabetes as implemented in SharedDiabetes among the GPs in the study. Their understanding is that only seldom the healthcare professionals share their care across sectors; instead they see the patient as either being treated at the outpatient clinic or at the GP's clinic for the time being. The diabetic patient, so to say, does not constantly move back and forth between the GP and the outpatient clinic.

From this perspective, it would make much more sense to devise IT support for exchanging data than to talk about shared care in the strict sense seen from the GP when talking about providing data for an epidemiological purpose. If the system is to support the GPs professional practice of providing care in collaboration with the patients themselves, then what is shared might differ quite significantly.
3. Conclusion

It is clear that a more efficient treatment of diabetes is required due to the rising number of diabetics and accompanied risks of late complications. The case described is a welcomed initiative in that direction. The system is technically sound and well designed, and the project demonstrates that many relevant and necessary steps have been taken. However, from the GP's perspective SharedDiabetes supports the regional outpatient clinics' monitoring of diabetes and provide data for proactive actions towards late complications. The system does not support the GPs' professional practice of dealing with diabetics due to a number of reasons: lack of need for shared care in terms of shared data, lack of attention to GPs medical practice, and lack of proper integration with the GPs' EPR systems.

Our analysis of the case study identified multiple levels of shared care: the national/regional level with a mainly epidemiological purpose and a local level centered around care of the individual diabetic patient. Shared care in the sense of providing care for the individual diabetic by a group of professional actors with different institutional belongings is certainly feasible but would require a different set up from the one described with SharedDiabetes.

Acknowledgments

We would like to thank Sine Marie Øelund and Louise Baunsgaard Koch who together with the second author, Maren Fich Granlien, have conducted the empirical study that formed the empirical basis for this paper.

References