The Use of Narratives in Medical Work: A Field Study of Physician-Patient Consultations

Troels Mønsted[1], Madhu C. Reddy[2] and Jørgen P. Bansler[1]

[1] University of Copenhagen, Denmark, [2] The Pennsylvania State University, USA

monsted@diku.dk, mreddy@ist.psu.edu, bansler@diku.dk

Abstract. Medical reasoning involves more than just summarizing clinical data and guidelines. Illness trajectories of chronic patients are often long, complex and full of uncertain information that requires interpretation. Understanding the complex interrelations is an important aspect of medical reasoning that displays narrative rather than scientific characteristics. While the qualities of the medical record as a repository of information or as a coordinative tool are well known, the role it plays in the unfolding of narratives in medical reasoning is less discussed. This paper examines this issue through a case study of patient consultations that take place as part of a distributed treatment of chronic heart patients. We found that the record, even though fragmented and to some extent incomplete, enables the physician to construct an *ad hoc narrative*. During the actual consultation, physicians and patients unfold a more detailed narrative, which we refer to as the *re-emplotted narrative,* that includes additional information and entails a collaborative exploration of uncertainties. While this may point to some inadequacies of the medical record as a supportive tool for the process of unfolding narrative, we suggest that is it in fact a crucial component of the medical reasoning activity that must be considered in design of supportive systems.

Introduction

Patient consultations are highly collaborative activities where the patients tell their story and describe their complaint, and the physician seeks to make sense of the patients' problem in medical terms and come up with a treatment plan. While the conventional view on medical diagnosis and decision making puts general scientific rules and knowledge at the forefront, patient consultations require much more than rule following and formal decision making, because the generalized knowledge of medical science must somehow be connected with the unique experience of the individual patient (Waymack 2009). Referring to Berg (1992), Kane and Luz (2009) argue that:

> "(…) a physician, in transforming a patient's problem into a solvable problem, does not simply combine some cognitive items together, such as historical and examination data, but actively articulates an array of heterogeneous elements within the transformation." (Kane and Luz, 2009:358)

According to Montgomery (2006), medical practice cannot be characterized purely as science or a technical skill, but as:

> "(…) the ability to work out how general rules – scientific principles, clinical guidelines – apply to the particular patient" (Montgomery, 2006 :5).

Rather than considering medical practice to be a science, it can be characterized as *medical reasoning* - an instance of practical reasoning, or in Aristotle's words, phronesis. Through medical reasoning, information is put together with conditional certainty (Hunter, 1996; Montgomery, 2006)

The narrative aspect of medical reasoning is mirrored in the primary tool for storing and conveying clinical information, the medical records. These documents have a strong narrative aspect because narratives supply a workable medium for representing knowledge that is time- and context-dependent – and often uncertain or ambiguous as well. They are created to organize, record and capture practical experience. Medical records are therefore far from a straightforward presentation of clinical data. As argued by Berg and Bowker (1997), a medical record embodies multiple, intertwined representations of the patient. These representations do not fully mirror the body of the patient, nor determine them. Instead they argue that the medical record:

> "(…) mediates the relations that it organizes, the bodies that are configured through it" (Berg and Bowker, 1997:514).

Likewise Fitzpatrick (2004) depicts medical records, not as passive information repositories, defined as the archival record, but as the *working record*, defined as:

> "a set of complexly interrelated clinician-centred documents that are locally evolved, maintained and used to support delivery of care (…)" (Fitzpatrick, 2004:291).

While researchers have studied how physicians through social behavior such as *mindfulness*, i.e. non-judgmental moment-to-moment awareness can assist the

unfolding of narratives (Conelly, 2005), much less has been reported on how the diverse clinical and narrative information stored and conveyed by medical records, is used in practice. This is however highly relevant for design of electronic patient records.

As argued by some (Arminen and Poikus, 2009; Hartswood et al, 2003), the design of medical systems is often based on flawed or overly simplified assumptions about the nature of clinical practices creating a mismatch between the presupposed and the actual use of a given system. Often technical solutions are posed as answers to inherently socio-technical problems (Hartswood et al, 2003). One common misconception, as argued by Paoletti (2009) is that information is *out there* to be used and processed in a linear diagnostic process, rather than being narrative information that require interpretation.

The study presented here examines the use and role of medical records in the collaborative unfolding of narratives at patient consultations. We examine this in the context of patient consultations taking place as part of the distributed treatment of chronic heart patients in Denmark. In this study, we are interested in developing a more detailed picture of how records are brought in play and how different kinds of content, clinical evidence and narrative information, affect the medical reasoning taking place.

The paper is structured as follows: In the following section, we elaborate on the concept of narratives in healthcare and related research on medical records. Next, we present our field study of consultations of chronic heart patients at a local hospital. We finally discuss how and to what extend the record support the narrative component of medical reasoning at patient consultations.

Background

Narratives in Clinical Practice

"Despite all the prohibitions against 'anecdotal knowledge' in medicine, case narration is the principal means of thinking and remembering – of knowing – in medicine. The interpretive reasoning required to understand signs and symptoms and to reach a diagnosis is represented in all its situated and circumstantial uncertainty in narrative." (Montgomery, 2006:46).

The notion of narratives is increasingly recognized as an influential concept in helping us understand reasoning processes, interaction and information sharing in healthcare settings. The concept has been applied at multiple levels of analysis. Recently, Hayes et al (in press) applied *narrative networks* as an alternative analytical lens to traditional workflow diagrams, to foreground how interrelating *narrative fragments* of many multiple stakeholders constitute a network that goes beyond the view of the individual healthcare practitioner. Some studies have

investigated the role, conditions for, and significance of *patient stories* and *storytelling* in medical practice from a patient perspective (e.g. Kleinman, 1988; Brody, 2003) while others have studied the role of narratives from the perspective of doctors (Hunter, 1991; Atkinson, 1995). In this paper focus on the body of literature concerning the role narratives play in medical reasoning.

The attention towards narratives is partly motivated by the challenging task it is for healthcare professionals to deal with and comprehend long *illness trajectories* that, following the definition of Strauss et al (1997) refers to:

> "(…) not only to the physiological unfolding of a patient's disease, but to the total *organization of work* done over that course, plus the *impact* on those involved with that work and its organization." (Strauss et al, 1997:8).

It is increasingly recognized that medical reasoning, without disregarding the scientific foundation of medicine, also has a strong interpretative, hermeneutic component (Lock, 1990). While healthcare professionals as argued by Mol (2002) configure their own experience of a given patient, and therefore see slightly different bodies and diseases, they still must position themselves in relation to a past and an anticipated future (Mattingly, 1998). An important question therefore is how healthcare practitioners make sense of a patient's illness trajectory.

Based extensively on the pioneering work of Weick (1995), several studies have portrayed the role of sensemaking in healthcare, focusing on patients' sensemaking of interactions with nurses (Hargle et al, 2009) and social and collaborative aspects among healthcare professionals (Albolino, 2007; Paul and Reddy, 2010).

As argued by Lock (1990), the concept of narratives embraces the diverse components of medical reasoning (Lock, 1990).

> "I will claim that narrative is a fundamental language event which allows the explanatory discourse of science and the meaningful discourse of human relations to be grafted onto it" (Lock, 1990:42)

According to Feldman et al. (2004) narrative form is not necessarily a neutral and fully inclusive story. Rather they define narratives as:

> "(…) a sequence of events, experiences, or actions with a plot that ties together different parts into a meaningful whole" and "(…) the narrative includes, excludes, and emphasizes, the storyteller not only illustrates his or her version of the action but also provides an interpretation or evaluative commentary on the subject" (Feldman et al, 2004:148).

The central, unifying structure of narratives is the *plot*. In contrast with the mere chronological account of events provided by *stories*, a narrator imposes a causal or moral structure to a sequence of events organized by the plot (Hydén, 1997, Hobbs, 2003). This configuration process, referred to as *emplotment*, is by Mattingly (1994) described as marshalling the relation of events to transform from mere sequence to causality. While emplotment can be an individual activity it often involves collaboration in healthcare settings. Brody (2002) have portrayed patients as active and important participants in the joint construction of narratives,

and according to Mattingly (1998) a narrative is often made through the combined efforts of all players, with the therapist in charge.

The Role of Records in Clinical Practice

Medical records are often thought of as a document containing all patient related information within an institution. They were initially introduced as educational tools, consisting of loosely structured descriptions of particular cases, authored retrospectively using a free-from narrative style (Siegler, 2010). The medical record has since evolved to be a highly formalized and structured document used actively in patient care. However, the medical record is far more than a single repository of information. As argued by Berg and Bowker (1997), the record consists of multiple bodies and is constituted by:

> "(…) all written, typed, or electronically stored traces of any aspect of patient treatment that has official status within the hospital system and is in principle stored for a period of time (at least equal to the patient's stay in the hospital" (Berg and Bowker, 1997:515).

This fragmentation of the medical record may be a product of increased complexity and a tendency towards distributing treatments across multiple, specialized healthcare providers, typically referred to as *shared care* (Pritchard and Hughes, 1995) or *integrated care* (Kodner and Spreeuwenberg, 2002). One strategy to meet an increased demand for collaboration across professional and organizational boundaries is to improve design of Electronic Medical Records (EMR). Winthereik and Vikkelsø (2005) argued that EMRs are important change agents that can help satisfy a growing interest in organizing care along the specific patient cases, rather than along organizational boundaries.

According to Berg (1999) medical records fulfill two important roles: They both accumulate information, and coordinate activities. The coordinative role of EMRs has been of major interest in CSCW research. Østerlund (2002) studied how records are used to convey information within and across organizational boundaries. Reddy et al (2001) studied the EMR as a *Common Information Space* that serves as an important resource of coordination among heterogeneous, physically co-located actors because of its ability to de- and re-contextualize information. Munkvold and Ellingsen (2007) have studied the benefits and limitations of Common Information Spaces to form links between the disconnected trajectories of different organizations along the overall illness trajectory of a patient.

While medical records fulfill a crucial role as coordinative artifacts, they also fulfill another – and just as important – role as "tools to think with". In other words, they act as artifacts that underpin the process of medical reasoning and facilitate the exercise of clinical judgment. Østerlund (2008) argued that records are important tools by doctors and nurses in their sensemaking activities. Some

studies suggest that the medical record may in fact be a poor resource for answers to the often very complex questions of physicians in their local practices (Gorman, 1995). Furthermore, these highly complex EMRs may draw physicians' attention away from the patient and therefore, hinder their engagement with the patient. However, relatively few studies address how medical records are used in medical consultations and how this complex information infrastructure supports medical reasoning and unfolding of narratives.

While the narrative content of medical records have been portrayed in some detail (e.g. Tange et al, 1997), much less have been reported on how the narrative aspect of medical reasoning is facilitated or mediated by technology.

Research Site

To inquire into the role of the medical record in medical reasoning during patient consultations, we studied a particular type of consultation, *the medical follow-up* of patients with implanted ICD device. An ICD (*Implantable Cardioverter Defibrillator*) is a programmable electric impulse generator. The ICD constantly monitors the heart and intervenes when it detects a pre-specified rhythmic abnormality, either by pacing the heart or by delivering an electric shock. ICD therapy is typically combined with medical therapy, often consisting of a cocktail of different drugs.

Due to a high degree of professional specialization, the care of ICD patients is distributed across multiple healthcare providers; consequently, the illness trajectory crosses several professional as well as organizational boundaries. Thus, ICD care in our study involves at least two hospitals, a general practitioner, additional home care, a rehabilitation unit, and other specialists. ICD care is therefore constituted by a number of independent but somewhat interdependent practices.

The main aspects of ICD care are provided by two hospital units. The responsibility for implantation and monitoring of ICD devices is carried out by one of the five national *ICD Centers,* located at major teaching hospitals in Denmark. In this unit, staff (physicians, laboratory technicians and nurses) specialized in electrophysiology, are responsible for ICD implantation and for monitoring the technical functioning of the device, the latter referred to as *device follow-ups*. These are either conducted as consultations or by a remote monitoring system, where the patients receive feedback while at their home.

The *local hospitals* are responsible for the rest of the patient's medical treatment. This is assessed at regular medical follow-ups, where the patient's progress is assessed and the treatment adjusted accordingly. Local hospitals are distributed widely across the country.

Methods

We used multiple methods to develop a rich picture of the use of records medical reasoning at patient consultations. The study involved a combination of observations, interviews, document and system studies and design workshops, conducted over a period of approximately 12 months. The observations were conducted over a two-day period where one researcher shadowed a physician conducting patient consultations. As part of the observations, the researcher conducted several informal interviews with the physician focusing on specific aspects of his practice, documents, and systems. We also examined the documents and the systems by conducting video-recorded walkthroughs in situ and by collecting and analyzing five full sets of progress notes from the medical records of ICD patients. The five design workshops, each lasting 2-3 hours, involved five physicians, representing two hospitals involved in ICD care, and five designers and researchers. The overall purpose of the workshops was to explore current practices and to develop concepts and prototypes for improving support of distributed ICD care. One central activity at these workshops was discussion and mapping of the current work practices and the information systems in use.

All consultations were audio- and video-recorded and were fully transcribed. All data have subsequently been categorized and analyzed through open coding and axial coding (Strauss and Corbin, 1998).

Participants

This paper focuses on medical follow-ups conducted at the local hospitals. The main participant in the study is a physician who we observed while he was conducting medical follow-ups. The physician is a trained cardiologist and is one of the leading specialists in ICD care at this particular hospital.

The patients involved in the study all suffer from chronic, severe heart arrhythmia. Approximately half of the patients have an implanted ICD device, while the others either have been or are considered potential ICD candidates. The group includes young patients in their thirties as well as middle-age and elderly patients. Their physical as well and mental capabilities varied from being severely impaired to being relatively well-functioning. Furthermore, some of the patients suffered from other chronic conditions, such as diabetes or COPD (Chronic Obstructive Pulmonary Disease). Although some of the patients attended the consultation individually, most brought a relative and/or a translator.

Tools

At the patient consultations, the physician has a broad selection of paper and IT-based information systems at his disposal. The backbone of the information infrastructure at the local hospital is a paper-based patient record, a cross-

departmental folder, used by all wards at the local hospital in which the patient is treated. The patient record can therefore grow to become a substantially sized document. The first section of the record containing the *progress notes* is particularly important to the physician. As we will later elaborate, the progress notes contain the narrative parts of a medical record, as opposed to other sections containing more quantitative clinical data. The progress notes are comments dictated by all healthcare professionals who interact with the patient. The notes summarize findings and decisions made at each event. In some cases, the progress notes also contain more substantial information, e.g. about the course of events in the patient's illness trajectory.

The physician also has a large number of IT-systems and dedicated databases at his disposal. During consultations, the physician will have approximately ten systems running on his computer. The most important systems are:

- *HjerterPlus* - an IT-based local, dedicated heart record.
- *Opus Notat*, - a system used to manage progress notes.
- *Labka* - a system that stores results from laboratory examinations.
- *EPM* - a system intended to provide a centralized list of medicine prescribed to a patient.
- *www.icddata.dk* - an online repository of ICD information containing information from the device follow-ups at the ICD.

Physician-Patient Consultations

Medical follow-ups take place at regular intervals, depending on the condition of the patient and the stage of the treatment. The purpose is to assess the patient's condition and progress and to adjust the medication accordingly. If the medical treatment is assessed to be optimal and the patient is in a stable condition, the consultations at the local hospital are discontinued and the patient is referred to follow-ups at his/her general practitioner. Under normal circumstances, 15 minutes is allocated for each consultation, the physician's preparation included. During our observations, the schedule was however frequently adjusted, either because of cancellations or extended consultations.

Before calling the patient to his office, the physician at the local hospital would usually prepare for the consultation by reading the medical record as well as any other information located in the IT systems. This was done to get an overview of the patient's current condition, illness trajectory and to identify important issues to address during the consultation.

> Before the consultation, the physician prepared by quickly reading the progress notes in the paper record and the online record of ICD information, www.icddata.dk. The patient, a male, had a biventricular ICD implanted in 2004. He does not suffer from ischemic heart disease. In 2008, the patient was admitted with a severely impaired condition. Treatment with beta-blockers was commenced in an attempt to improve his condition, but this was made difficult

due to the patient's hypertension. The patient' EF value was 10 the last time it was measured. The physician furthermore found a medicine list in the record. Finally, the physician learned that the patient hadn't recently received ICD therapies.

The record provided the physician with a general overview of the history of significant events in the illness trajectory. Also, more specifically, it pointed out the treatment with beta-blockers as an area of concern that he should attend to during the consultation. During his preparation, the physician would usually take short notes on a printout of the scheduled consultations. This annotated printout came to represent his summary of the patient's illness trajectory.

When prepared, the physician calls the patient to his office. During our observations, the physician most often initiated the consultation by first highlighting his understanding of the patient's condition and then asking a set of routine questions.

> The physician initially told the patient that he had read his record and medicine list, and that he could see that the patient had been very ill, but also that his condition had improved. He then commented that the patient didn't have shortness of breath from walking to his office. The patient confirmed this and furthermore told the physician, that he can walk around effortlessly, unless the weather is cold. The physician also asked and received confirmation that the patient did not experience chest pains. Finally the physician told the patient that he could tell from the record that the medicine the patient was taking was working well.

The questions asked by the physician are important for his assessment of the patient's condition. As part of this routine, the physician also measures the patient's blood pressure and pulse and on some occasions conducts other forms of physical examinations. After these initial steps, consultations can proceed in a variety of ways. Often, the physician's questions will unveil symptoms or conditions that need further examination. On other occasions, they trigger the patient to tell the physician about his own experience or concerns.

> During the conversation, the patient told the physician that the beta-blockers caused strong side effects. He stated that he experienced fatigue and troubled bowel movements from the particular beta-blocker he was taking, drug A. He furthermore expressed strong concerns that his body couldn't tolerate all this medicine. Because of the patient's discomfort, the physician suggested replacing drug A with another beta-blocker, to which the patient reluctantly agreed. The physician first suggested drug B. The patient, however, recalled that he had already previously tried this drug and that it too had strong side effects. This pattern repeated when the physician suggested drug C, although the patient said that it had been a long time since he had tried this drug. The physician suggested that he try it once more, because his body might have adjusted to the new situation. After some consideration, the patient agreed to try drug C again.

As is often the case during consultations, the patient pointed out a relevant issue – what particular drug to use – that needs to be addressed. Furthermore he provided the physician with information that was highly relevant for physician's medical reasoning, namely that the medication adjustment attempts were not only affected by his physical problems but also by his experiences with the side effects. The patient also provided the physician with a historical account of the types of drugs that had taken previously. In this case, this information and

discussion lead to a more informed decision of re-prescribing one of the previously attempted drugs.

Towards the end of a consultation, the physician and the patient agree on the outcome of the consultation, e.g. new treatment initiatives or other examinations that the patient might need. The physician gives the patient prescription for medications and lab work and schedules the next consultation. As the last part of the routine, the physician will dictate a progress note that a secretary will later enter in the medical record. These progress notes cover a brief description of the patient's condition, provide detailed list of prescribed medicine and diagnostic codes. The progress notes also often point to uncertainties or aspects of the patient's treatment that the physician wants future caregivers to examine when seeing the patient.

Findings

During the medical follow-up, clinical evidence played an important role: the physician's decision to advise the patient to recommence treatment with beta-blockers was partially based on clinical guidelines. This scientific foundation was central to his argument to the patient in one consultation where he advised a patient to disregard his anxiety and take a prescribed type of medicine in spite of strong side effects:

> "All research show that it is the medicine that causes people to live longer and prevent them from being admitted to a hospital again" (Physician)

In other consultations, we observed the use of the *echocardiogram* – an examination that among other things is used to determine the EF value (*ejection fraction* or popularly the *pump function*) of a heart. According to the physician, the echocardiogram is *"the keyword in all our algorithms"*. It is used to indicate if the patient is an ICD candidate, and to assess the progress of the treatment. If the patient during the consultation is diagnosed with hypertension, the patient will usually be advised to begin treatment with antihypertensive medicaments. This medical treatment will be adjusted until the physician assesses the patient to be *optimally treated*, which means that the dosage reaches a level defined on the basis of clinical evidence and particularities of the patient.

The decision to prescribe the beta-blocker, drug C, described in the section above displayed certain narrative characteristics. The outcome of the consultation was not only a product of compilation of clinical facts but also involved assessment and interpretation of causality in clinical information that is equivocal or not recorded in full detail, social and contextual factors and the experience of the patient. An important prerequisite for this kind of medical reasoning is that the physician, building on insight in both the patient's clinical condition and the patient's experiences, is able to configure relevant elements of the patient's illness trajectory into a meaningful narrative.

Due to the chronic condition of ICD patients, and the fact that patients with chronic heart arrhythmia often suffer from other chronic illnesses, the medical records often contain large number of pages. The same is true for the other systems where patient data are registered. The challenge for the physician during the consultations is to identify relevant elements of the patient's illness trajectory and through emplotment construct a narrative that explains relevant causal relations. This narrative is highly context dependent and we refer to it as the *ad hoc narrative*.

In the following sections, we highlight how the ad hoc narrative emerges within the medical follow-up. First, we examine how narratives reside in the medical record, and then demonstrate how the narrative is unfolded during consultations.

Narratives in the Medical Record

The multiple documents and systems that constitute the medical record used during medical follow-ups reveal the complex nature of medical reasoning. Due to the scientific component of medical work, a substantial amount of the information stored in the record can be characterized as clinical evidence. The paper record will for instance often contain a printed echocardiogram and extensive medicine lists, while adjacent IT systems such Labka and www.icddata.dk, respectively, contain results from laboratory tests and highly condensed information, primarily numeric, describing the functioning of the ICD device.

The progress notes in the paper records, one of the more prominent components in use at the medical follow-up, displays more narrative properties. Since progress notes are dictated after every contact with the patient, they can vary greatly in format and content depending on the author and particular issue dealt with during the consultation.

Some progress notes contain very concise data on the patient's current condition and state of the treatment. This type of progress notes report on a narrow set of issues concerning the particular consultation:

As of today, patient attended a consultation with a nurse in the heart failure clinic.
The patient's son took part in the consultation.
See HjerterPlus under standard forms.
Blood pressure 120/60. Weight 65,9 kg NYHA 1.
Pt is in a good state of health.
Plan: Cres Caps. Odric 2mg x 1 vesper.
Ct. other medicine unchanged.
Pt. have appointed with physician at 8/10 09.
Pt. gives consent to the above mentioned.

However, some progress notes have a more narrative character and reveal fragments of the patient's past illness trajectory, particular findings that influence

the treatment plan, and uncertainties that must be taken into consideration. These progress notes, therefore, not only provide the reader with clinical facts, but also provide parts of the context surrounding the medical reasoning performed at a particular consultation.

> Pt was admitted with incompensation for 6 months ago, presumably with secondary to paroxysmal atrial fibrillation.

> EF was 25% and there was light mitral insufficiency and severe pulmonary hypertension. KAG was attempted, but could not be accomplished due to severe calcification of a. femoralis. It has been decided to complete the medical treatment alone. Pt has tolerated the treatment well under NYHA class 1-2, no chest pain or syncopes. Blood samples not abnormal. Blood pressure 140/60, pulse 75 beats per minutes.

> (This was followed by a comprehensive medicine list)

A progress note like this one positions specific events in the patient's illness trajectory and explains the causal relationships and interdependencies among particular parts of the patient's treatment. In isolation, the example, presented above, only provides the physician with a description of a minor fragment of the patient's illness trajectory. When combined with other similar progress notes, the physician is however able to construct a timeline of events and interdependencies, which is why the progress notes can be important resource for the physician. They are used in unfolding of ad hoc narratives.

A less common but interesting subcategory of progress notes is referred to by the physicians as *summaries*. Summaries are rich accounts that contain a substantial description of the patient's illness trajectory. A summary is often produced in response to certain events that require the responsible professional to develop detailed insights into the patient's illness trajectory. For instance, summaries are written when the patient is (re-)admitted, referred to other healthcare providers or, more broadly, in situations in which significant decisions have to be made. One common feature of summaries is that they provide a relatively comprehensive description of the patient's condition, the illness trajectory, and contextual information. Although the content and format may vary they provide information on allergies, past events, cardiological risk factors, current condition, other medical conditions, medicine, social situation, objective findings and the author's conclusion.

All progress notes including summaries are entered into the medical record as part of or immediately after a triggering event. Consequently, at the medical follow-up, the physician dictated the progress notes immediately after the consultation. The narrative content of progress notes in general and summaries in particular are a textual representations of ad hoc narratives unfolded during medical reasoning processes, e.g. at patient consultations. We refer to them as *textual narratives*. Though the content of textual narratives is framed by a particular event, they are often important resources for medical reasoning at other patient consultations.

Unfolding the Narrative

The main objective of a patient consultation is to adjust aspects of the treatment to improve the patient's condition. A significant aspect of this is the physician's attempts to make sense of the patient's current condition and identify relevant aspects of the past illness trajectory – which we refer to as *unfolding the ad hoc narrative*. During our study we observed that this emplotment process happened in two stages: Prior to the consultation the physician constructed a *proto-narrative* – a narrative based solely on information found in the medical record, either clinical data or textual narratives. During the consultation the proto-narrative was corrected or refined through physician-patient interaction – what we refer to as *re-emplotment*. An important resource during re-emplotment was the *patient's narrative* – the patient's own configuration of significant events and experiences from his/hers illness trajectory. In the following two sections we elaborate on these two observations.

The Proto-narrative

Before a consultation, the physician began to read the progress notes in the medical record, and explained to the researcher:

> "We have a nineteen hundred pages record here [presumably an ironic exaggeration]. I can't remember that I've seen him before. Okay. There is a note from December where we have summarized a bit. December 08, more than a year ago. There is also a very good summary if we go back to March 08." (Physician)

During his preparations, the paper record, and in particular the progress notes are important resources for the physician. According to the physician, he will usually first look through the most recent progress notes in search of a summary, since it will provide him with a relatively thorough overview. Summaries are, however, often not available or too old to provide information on more recent developments. In those situations, the physician instead has to construct the proto-narrative from the often more fragmented short progress notes based on previous consultations and hospital admissions. Depending on the particular situation, he may also use one or more of the dedicated IT systems or databases. In this way, he is able to construct an overview of the more significant events in the patient's illness trajectory. When constructing the proto-narrative, the physician configures a plausible narrative from often incomplete, ambiguous, and even contradictory information from multiple sources. In this process, the physician seeks to find answers to questions such as 'what happened, when, how and why?' He furthermore identifies significant events and makes decisions on which information to include, exclude, stress, or subordinate. Finally, he arranges events in a certain order that implies a particular causality.

The physician stated that he would prefer to have this proto-narrative prior to the actual consultation. However, he can also construct it while the patient is

present. In the following example, the physician constructed and articulated the proto-narrative to the patient at the beginning of a consultation:

> "I will just summarize what we know about you, so you can correct it if we have gotten some of the facts wrong. It is a long story. Blood clot in the heart in 2002, where a "balloon treatment" was attempted. Blood clot again in 2005, where a new "balloon treatment" was attempted, but it didn't really succeed. Then you had a bypass operation. Then came a blood clot in the head. Then a new coronary angiography in 2006. Then we know that you have decreased pump function in the heart, which is why you got this ICD device. You were admitted in 2008 where we made a new coronary arteriography of the carotid artery. Nothing has changed here. This [implicitly the observed consultation] is only about the medical treatment of the heart. I can see that you have talked to (name of other physician at the cardiology ward at the local hospital) recently. Three or four weeks ago?" (Physician)

By combining information from multiple sources (i.e. several progress notes), the physician actively constructed a proto-narrative with a clear plot. The purpose was to organize, make sense of and explain causalities in the available data on the recent developments in the patient's condition and treatment. In this case, the physician identified relevant but incomplete information, namely the patient's recent and apparently non-routine consultation with a cardiologist at the same ward at the local hospital. However, the purpose and outcome of the consultation was not described in the record.

The Re-emplotted Narrative

The consultation often begins with the proto-narrative because the physician usually initiates the conversation by explaining the account he has just constructed to the patient. The ensuing conversation leads to an elaboration of issues raised in the proto-narrative based on the *patient's narrative*. Continuing the example above, the patient provided additional information about the outcome of the recent consultation:

> The patient explained that drug A was changed into drug B at the recent consultation, although he hadn't yet commenced this treatment, because the medicine is incredibly expensive. The physician asked whether or not he had applied for an economic subsidy. The patient confirmed that this application was in progress. The physician then informed the patient that he would get the subsidy retroactively, so, he could initiate the treatment immediately. The patient was unaware of this.

In other situations, the patient's narrative brings up issues not described in the proto-narrative, e.g. personal concerns and questions or conditions and clinical facts that initially were left out by the physician.

> In one consultation, a patient expressed concerns over the dosage of one of the drugs he was taking, drug A, an antihypertensive medicament. The patient stated that, *"as far as I understand, it should not be so high"*. After the physician had clarified that the patient referred to a measure of his blood viscosity and not the dosage of the drug, the patient stated that he believed it to be *"three point something"*. According to the physician, this measure should preferably be between 2 and 3. He therefore examined the latest blood tests using the Labka system and found that this number was in fact 4.1, which under normal circumstances would

require adjustment of the medicine. The patient stated that the medicine was not adjusted at a recent consultation with a nurse, and he did not believe that she had taken this into consideration. Since neither of the systems available at the office provided information on this consultation, the physician had to leave the consultation, to procure the nurse's record, which is a separate document. When he returned approximately five minutes later, he had clarified that the responsible nurse was in fact aware of the high blood viscosity, and that the medicine had been adjusted accordingly. They did, never the less, agree on a slight adjustment to the medicine.

In this situation, the re-emplotted narrative included perspectives from the medical record and the patient's knowledge and concerns. It also came to include perspectives, rationalities and causal explanations of healthcare professionals, who were not present or directly represented through any parts of the medical record. The patient's narrative thus pointed out areas of concern that required elaboration.

During the consultations, we observed that the re-emplotted narratives provided the physician with relevant information that initially had been missing in the proto-narrative. The consultations also involved a collaborative exploration of information that was inaccurate or missing. This narrative re-emplotment is therefore not only about filling out information gaps but involves a set of interactions where parts of the story are further explored, specified and reshaped. This adds a layer of social interaction to the medical reasoning activity.

After all medical follow-ups, the physician dictates a new progress note that is later be transcribed by a secretary and placed in the medical record. Apart from a medicine list, a set of diagnostic codes, and information about the decisions made at the medical follow-up, this progress note contains a brief summary of the physician's view of the patient's illness trajectory. In this way a textual narrative is created on the foundation of the ad hoc narrative unfolded during the consultation. This textual narrative may potentially become a resource for unfolding ad hoc narratives at future consultations.

Discussion: The record as supportive tool for unfolding of narratives

Our studies of medical follow-ups show that while clinical facts and guidelines play a crucial role for the outcome of consultations, many decisions rest upon a far more complex process of medical reasoning. For instance, medicine prescriptions are highly influenced by clinical guidelines for chronic heart patient care, but involve other considerations as well, e.g. contextual factors such as other health related conditions as well as observations and interpretations from other healthcare professionals. A prerequisite for medical reasoning is, therefore, that the physician not only has access to clinical facts, but also that he is able construct a plausible account of events and establish causal relations regarding the patient's

illness trajectory. This is what we refer to as the *ad hoc narrative*, which is compiled through a partly collaborative process.

As described in the previous section, the process of unfolding narratives is a convoluted and sometimes difficult activity for the physician. During his preparations prior to a consultation, the physician explained it to the researcher in this way:

"I guess you can see, that when I am trying to get the overview here… This one only goes back to 2007, so it really isn't that long. I need to get an overview of the patient and I could start from one end, but I can't stand that. The original progress notes goes from 2007 to 2009. That's 70 pages. Then we changed to a new system, and then the record goes on with another 23 pages. That's 93 pages, right. Then it would be nice with a short summary." (Physician)

To produce a proto-narrative, the physician must in a matter of minutes look at several documents and systems, select a small subset of information from a large, fragmented body of patient data and position these in the overall illness trajectory to form a narrative of a patient's chronic heart condition. Considering the complexity of this practice, the medical record and in particular the progress notes serve remarkably well as conveyors of information.

Our study did, however, also reveal some significant limitations. The proto-narratives produced by the physician prior to the consultation rarely proved a fully comprehensive account. Often, clinical data from the local hospital and other healthcare providers were left out and some of the included information proved to be out of date. Furthermore, narrative information such as the assessments of other healthcare providers and the patient's own knowledge, experience and anxiety were often not detailed. One explanation for the medical record's apparent inadequacies as a supportive tool for the unfolding of narratives may be that the medical follow-ups were situated in a distributed and somewhat fragmented practice.

The healthcare providers involved in ICD therapy use and maintain a broad array of documents and systems that are not well integrated. In this context, very little information migrates across platforms and even less across organizational boundaries. The backbone of the local hospital's information infrastructure is the paper-based medical record. Although some information from adjacent systems can appear in the paper record, either as printouts placed in the folder or in progress notes, patient information is fragmented into multiple systems and documents. At the medical follow-ups, physicians may use up to ten documents or systems to gather important information. Gaining an overview of this variety of information in a short period of time is in itself a cumbersome task. Furthermore, similar sets of documents and systems with much of the same information may be maintained by other healthcare providers e.g. the ICD Center.

As shown by figure 1, only a few systems are designed to support coordination and convey information across the organizational boundary: The computer system 'Opus Notat' is primarily used to manage local progress notes, although it also enables the user to access progress notes from other hospitals. The online

database 'www.icddata.dk' contains subsets of information from the device follow-up that can be accessed by physicians at the local hospital. However, this information is highly specialized, and will often require extensive background knowledge correctly interpret. Finally, the medicine database 'EPM' is intended to constitute centralized, single list of medicine prescribed to the patient. The system is however relatively time consuming to use, which is why it is not updated regularly. Therefore, the information contained in EPM is likely to be incomplete.
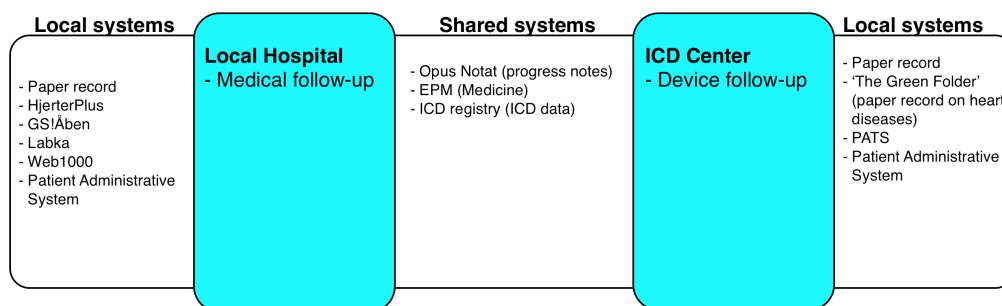

Figure 1. Fragmentation of the medical record

The current medical record in distributed ICD care is relatively fragmented, with patient information distributed across a number of poorly integrated systems. Therefore, the medical record provides healthcare providers with data that is potentially incomplete. It also functions poorly in supporting coordination across organizational boundaries. This is a generally recognized as a risk in healthcare, since lack of coordination can lead to organizational fragmentation and lack of continuity of care (Cebul et al, 2008). While the ad hoc narrative can to some extent be viewed as a symptom of the limitations of the medical record, it should also be considered to be a necessary and even desirable component of medical reasoning. The collaborative unfolding of the ad hoc narrative often adds information such as updated medicine lists. However, our study suggests that the process of unfolding the ad hoc narrative does more than just provide the physician with missing information. It also often provides a more appropriate plot of the patient's condition. This *emplotment* process is only partially supported by the medical record. The record provides the physician with information about the patient's illness trajectory and may provide cues to what is uncertain or untold. However, the complexity and fragmentation of the record makes it difficult to gain full insight into the patient's condition within the relatively limited time span of a medical follow-up without the collaborative unfolding of the ad hoc narrative.

Conclusion

The narrative component of medical reasoning permeates the activities, the interaction, and the medical record used in patient consultations. In this study, we focused on medical follow-ups taking place as part of a distributed treatment of chronically ill heart patients with an implanted ICD device. The goal of these consultations is to assess the condition and progress of the patient, and adjust the medical treatment accordingly. Due to the long illness trajectories, the fact that ICD patients often suffer from multiple chronic conditions and the distributed and somewhat fragmented nature of ICD care, a crucial task for the physician is to construct a plausible account the patient's current condition as well as past events that may influence the outcome of the consultation. This process involves more than merely accumulating clinical facts. To ensure continuity of care, the physician must make sense of incomplete information, contextual factors, assessments from other healthcare providers, the outcome of recent events and not least the patient's own experiences and concerns. A prerequisite for medical reasoning at such patient consultations is, therefore, to unfold an ad hoc narrative.

We found that the ad hoc narrative was typically unfolded in two stages: First, the physician would construct the *proto-narrative* based on information found in the medical record. The medical record supports this process relatively well, although it's substantial size and fragmented nature makes it virtually impossible for the physician to gain full insight in the patient's illness trajectory. As a result, the proto-narrative is often incorrect or imprecise. During the consultation the *re-emplotted narrative* is unfolded through interaction between the physician and the patient. Beside of including information that was either overlooked by or unavailable to the physician when unfolding the proto-narrative, unfolding the re-emplotted narrative is a way to construct a plot that is more appropriate for the particular consultation.

Acknowledgments

References

Albolino, S., Cook, R., and O'Connor, M. (2007): 'Sensemaking, safety, and cooperative work in the intensive care unit', *Cognition, Technology & Work*, vol. 9, no. 3, pp. 131-137.

Arminen, I. and Poikus, P. (2009): 'Diagnostic Reasoning in the Use of Travel Management System', *Computer Supported Cooperative Work*. Vol. 18, no. 2, pp. 251-276.

Atkinson, P. (1995): *Medical Talk and Medical Work*. SAGE Publications, London.

Berg, M. (1992): 'The Construction of Medical Disposals', *Medical Sociology and Medical Problem Solving in Clinical Practice. Sociology of Health and Illness,* vol. 14, no. 2, pp. 151–180.

Berg, M. and Bowker, G., C. (1997): 'The Multiple Bodies of the Medical Record: Toward a Sociology of an Artifact', *The Sociological Quarterly*, vol. 38, no. 3, pp. 513-537.

Berg, M. (1999): 'Accumulating and Coordinating: Occasions for Information Technologies in Medical Work', *Computer Supported Cooperative Work*, vol. 8, no. 4, pp. 373-401.

Brody, H. (2002): '"My Story Is Broken; Can You Help Me Fix It?" Medical Ethics and the Joint Construction of Narrative', In K. W. M. Fulford, D. L. Dickenson, and T. H. Murray (eds.): *Healthcare Ethics and Human Values: An Introductory Text with Readings and Case Studies*, Blackwell Publishers Ltd, Malden, Massachusetts, 2002, pp. 133-140.

Brody, H. (2003): *Stories of Sickness*. Oxford University Press, New York.

Cebul, R. D., Rebitzer, J. B., and Votruba, M. E. (2008): 'Organizational fragmentation and care quality in the U.S. healthcare system', *Journal of Economic Perspectives*, vol. 22, no. 4, pp. 93-113.

Conelly, J. E. (2005): 'Narrative Possibilities. Using Mindfulness in clinical practice', *Perspectives in Biolology and Medicine*, vol. 48, no. 1, pp. 84-94.

Feldman, M. S., Sköldberg, K., Brown, R. N., and Horner, D. (2004): 'Making Sense of Stories: A Rhetorical Approach to Narrative Analysis', *Journal of Public Administration Research and Theory Journal of Public Administration Research and Theory*, vol. 14, no. 2, pp. 147-170.

Fitzpatrick, G. (2004): 'Integrated care and the working record', *Health Informatics Journal*, vol. 10, no. 4, pp. 291-304.

Hargle, O., Brataas, H., and Thorsnes, S. (2009): 'Cancer patients' sensemaking of conversations with canser nurses in outpatient clinics', *Australian Journal of Advanced Nursing*, vol. 26, no. 3, pp. 70-78.

Hartswood, M., Procter, R., Rouncefield, M., and Slack, R. (2003): 'Making a Case in Medical Work: Implications for the Electronic Medical Record', *Computer Supported Cooperative Work*, vol. 12, no. 3, pp. 241-266.

Hayes, G. R., Lee, C. P., and Dourish, P. (In Press): 'Organizational routines, innovation and flexibility: the application of narrative networks to dynamic workflow', *International Journal of Medical Informatics*.

Hobbs, P. (2003): 'The Use of Evidentiality in Physician's Progress Notes', *Discourse Studies*, vol. 5, no. 4, pp. 451-478.

Hunter, K. M. (1991): *Doctors' Stories: The Narrative Structure of Medical Knowledge*, Princeton University Press, Princeton, New Jersey.

Hunter, K. M. (1996): 'Narrative, Literature, and the Clinical Exercise of Practical Reason', *The Journal of Medicine and Philosophy*, vol. 21, no. 3, pp. 303-320.

Hydén, L.-C. (1997): 'Illness and narrative', *Sociology of Health and Illnes'*. Vol. 19, no. 1, pp. 48-69.Kane, B. and Luz, S. (2009): 'Achieving Diagnosis by Consensus', *Computer Supported Cooperative Work*, vol. 18, no. 4, pp. 357-392.

Kleinman, A. (1988): *The Illness Narratives. Suffering, Healing & the Human Condition*, Basic Books.

Kodner, D. L. and Spreeuwenberg, C. (2002): 'Integrated care: meaning, logic, applications, and implications - a discussion paper', *International Journal of Integrated Care*, vol. 12, no. 2, pp. 791-806.

Lock, J. D. (1990): 'Some Aspects of Medical Hermeneutics: The Role of Dialectic and Narrative', *Theoretical Medicine*, vol. 11, pp. 41-49.

Mattingly, C. (1994): 'The Concept of Therapeutic 'Emplotment'', *Social Science & Medicine,* vol. 38, no. 6, pp. 811-822.

Mattingly, C. (1998): *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*, Cambridge University Press, Cambridge.

Munkvold, G. and Ellingsen, G. (2007): 'Common Information Spaces along the illness trajectories of chronic patients, *Proc ECSCW 2007*, pp. 291-310.

Mol, A. (2002): *The Body Multiple: Ontology in Medical Practice*, The Duke University Press, Durham and Londong.

Montgomery, K. (2006): *How Doctors Think. Clinical Judgment and the Practice of Medicine*, Oxford University Press, New York.

Paoletti, I. (2009): 'Communication and Diagnostic Work in Medical Emergency Calls in Italy', *Computer Supported Cooperative Work*, vol. 18, no. 2-3, pp. 229-250.

Paul, S. A. and Reddy, M. C. (2010): 'Understanding Together: Sensemaking in Collaborative Information Seeking', *Proc. CSCW 2010*, pp. 321-330.

Pritchard, P. and Hughes, J. (1995): Shared Care: The future imperative?, The Royal Society of Medicine Press.

Reddy, M. C., Dourish, P., and Pratt, W. (2001): 'Coordinating Heterogeneous Work: Information and Representation in Medical Care', *Proc. ECSCW 2001,* pp. 239-258.

Siegler, E. L. (2010): 'The Evolving Medical Record', *Annals of Internal Medicine,* vol. 153, pp. 671-677.

Strauss, A. L., Fagerhaugh, S., Suczek, B., and Wiener, C. (1997): *Social Organization of Medical Work,* Transaction Publishers, New Brunswick, New Jersey

Strauss, A. and Corbin, J. (1998): *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory,* Sage Publications, Inc.

Tange, H. J., Hasmana, A., Robbéb, P. F. d. V., and Schoutenc, H. C. (1997): 'Medical Narratives in Electronic Medical Records', *International Journal of Medical Informatics,* vol. 46, no. 1, pp. 7-29.

Winthereik, B. R. and Vikkelsø, S. (2005): 'ICT and Integrated Care: Some Dilemmas of Standardising Inter-Organisational Communication'. *Computer Supported Cooperative Work,* vol. 14, no. 1, pp. 43-67.

Østerlund, C. S. (2002): *Documenting Dreams: Patient-Centered Records versus Practice-Centered Records*, Sloan School of Management (Organization Studies Group). PhD dissertation.

Østerlund, C. S. (2008): 'Documents in Place: Demarcating Places for Collaboration in Healthcare Settings', *Computer Supported Cooperative Work*, vol. 17, no. 2-3, pp. 195-225.

Weick, K. E. 1995 Sensemaking in Organizations. Sage Publications.

Waymack, M.H. (2009): 'Yearning for Certainty and the Critique of Medicine as "Science"', *Theoretical Medical Bioethics,* vol. 30, pp. 215-229.