Keeping Distributed Care Together: Medical Summaries Reconsidered

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Abstract Summaries in the medical record have traditionally offered health professionals good cognitive support by guiding reading of the medical record and supporting communication and collaboration in clinical teams. However, because of increased distribution of chronic care and fragmentation of the medical record, summaries are becoming increasingly incomplete and have lost some of their ability to mediate collaboration in clinical teams and support situated sensemaking. Based on findings from a project aimed at studying and designing IT to support collaboration among health professionals in distributed, chronic care, this article present a detail study of current use of summaries and discusses how a new type of summary can be designed to offer better support for distributed, chronic care. Overall I argue that we must maintain an appropriate balance between structure and flexibility, while reconsidering the readership, the authorship, and the maintenance of summaries.

Introduction

Modern medical work at hospitals offers a great deal of interdisciplinary collaboration; most types of care involve several individuals that usually represent different professional groups, including physicians, nurses, secretaries, laboratory technicians, etc. Traditionally, collaboration at hospitals has mainly taken place within the boundaries of a single organization, either collocated or inter-departmental; care has been organized so that a patient was admitted, then treated by a clinical team, and then either discharged or referred to another care provider. As a result, information systems have typically been anchored locally, as exemplified by the widespread paper-based medical records, and primarily served to support work and collaboration within the confines of a single organization.

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In recent years, there has been a strong trend towards distributing care across multiple care providers through closer integration of primary and secondary care and through distribution of dedicated responsibilities among highly specialized teams working at different hospitals. This is partly motivated by increased professional specialization in healthcare. Furthermore, the healthcare system feels the pressure of an ageing population where more citizens suffer from (several) chronic conditions. This has made it necessary to consider how chronic care can be reorganized to meet both the requirements of quality and efficiency of care.

Distributed chronic care critically exposes the challenges in modern healthcare, as inter-organizational collaboration is currently not well supported by information systems; rather, the information infrastructure in Danish healthcare appears as a silo-based and fragmented cluster of records and IT systems (Bansler et al. 2013). Partly sparked by the chronic care model (Wagner et al. 1996), increased attention is paid to the re-organization of chronic care and how development of a new and better information infrastructure can contribute to increased continuity and quality of care. The chronic care model suggests that greater emphasis is placed on making patients active contributors to own care, for instance by learning self-management skills (by monitoring important symptoms, talking to physicians, and using resources in society), and by creating better collaboration and coordination among health professionals (Wagner et al. 1996; Roland 2013). As argued by Winthereik and Vikkelsø (2005), health information systems have great potential as change agents in our attempts to achieve a greater integration between the multiple health providers involved in care of chronic disease, and thus design and development of improved information infrastructures are key challenges to the continuous development of healthcare. In particular, development and redesign of medical records are challenging as this infrastructure has ramifications to practically all types of work at hospitals; medical records fulfill administrative and legal purposes, they serve as a means to support clinical research, quality assessment, to communicate observations, to justify decision and to coordinate activities (Rosenbloom et al. 2010).

For health professionals, medical records are probably the single most important information device; they are used to write and read patient information (Berg 1996), and to position their activities in relation to a past illness trajectory and an anticipated future (Mattingly 1998). The institution of the medical records is, however, for several reasons, under severe pressure: First, more patients suffer from chronic conditions. As a consequence, illness trajectories become longer and produce more information. Second, increased use of e.g. illness-specific databases, specialism-centric systems and stand-alone devices means that the medical record as a single, centralized artifact has seized to exist. Today, records can rather be understood as a distributed system or ecology of artifacts (Fitzpatrick 2004; Bardram and Bossen 2005) that, in the words of (Berg and Bowker 1997: 515) encompass "(…) *all written, typed, or electronically stored traces of any aspect of patient treatment that has official status within the hospital system* (…)". To achieve overview of a patient case, health professionals therefore currently gather information and assemble narratives from many different artifacts and systems

(Bossen and Jensen 2014). Third, due to increased specialization of clinical work and a trend towards centralizing clinical competences, courses of treatment are increasingly distributed as patients are treated by specialists at different units. This is often referred to as Integrated Care (Kodner and Spreeuwenberg 2002). As a result of these trends, the medical record has become obese and fragmented (Bansler et al. 2013) and for health professionals, it is now a rare privilege to have access to a complete set of patient data, let alone that this is presented in a digestible format.

In recent years, the issue of how clinical data can be rendered reusable in medical records, among other reasons, to counter the possible danger of developing information silos in healthcare has received great attention. In this regard, Rosenbloom et al. (2010) argue that the tension between structure and flexibility must be taken into account. While a high degree of structure and standardization is typically favored by those who reuse data, flexibility and narrative expressivity are often valued by busy writers of clinical notes (Rosenbloom et al. 2010). Yet, there is a tendency towards more structuring of new generations of medical records, as seen by numerous implementations of medical records that, as a consequence, are found typically to offer better support for secondary work (audit, administration, research, reimbursement), rather than primary medical work (diagnostic work, patient consultations, operations, examinations, etc.) (Greenhalgh et al. 2009), for instance by increasing time taken to retrieve information (Car et al. 2008) and by not offering sufficient cognitive support (Stead and Lin 2009).

This tension between structure and flexibility of clinical information systems, I argue, is deeply rooted in a more fundamental tension between different logics of medical work and on different ideas on how medical records serve clinical practice.

Different Logics of the Medical Record

The medical record is often portrayed as a repository of information that serves to provide health professionals with the best possible overview of patient information, to support them in making good clinical decisions. This logic suggests a strong foundation in the biomedical tradition where medical reasoning is portrayed as the practical application of scientific knowledge. Exemplified by the evidence-based regimen (Sackett et al. 1996) this implies "(…) *the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research*" (Sackett et al. 1996).

From this stance, medical work is about the application of clinical guidelines that mandates therapy to achieve a precisely defined target (Singer et al. 2002). The main virtue of the record is to support medical work providing an accurate account of patients and illnesses (Berg 1997), and the core of the medical record

is structured data that can be reused for many different purposes. This logic is more often than not strongly influencing health IT development. For instance, Greenhalgh et al. (2009) found six assumptions that characterize development of medical records in the UK (in this case specifically electronic medical records). These describe how records are predominantly seen as a container for patient information that can seamlessly be integrated in clinical work, and improve effectiveness and efficiency of clinical work. Hereby, new generations of medical records are expected to drive changes in staff and patient interactions and replace most, if not all, previous systems, and this centralized information infrastructure will gain value, the more distributed and widespread it becomes (Greenhalgh et al. 2009).

Second, other portraits of the medical record dispute the idea that data can be extracted, transferred and reused while retaining its meaning. Greenhalgh et al. (2009) conclude that "(…) *clinical data must be interpreted in context and "framed" before they become meaningful.*" (Greenhalgh et al. 2009: 763). Decontextualized clinical information therefore needs to be re-contextualized (Reddy et al. 2001) and 'universal codes' need to be localized (Winthereik 2003).

Following this logic, medical reasoning cannot be characterized purely as the application of science or technical skills, but "(…) *the ability to work out how general rules—scientific principles, clinical guidelines—apply to the particular patient*" (Montgomery 2006: 5), and perspectives on *sensemaking* (Weick 1995) are increasingly portrayed in literature (see e.g. Jensen and Aanestad 2006; Albolino et al. 2007; Battles et al. 2006; Jordan et al. 2009). Clinical guidelines do therefore not *mandate* care but are an important resource for situated medical reasoning where information is put together with conditional certainty (Hunter 1996; Montgomery 2006). This position goes hand in hand with a logic of medical records that to a lesser extent emphasizes its ability to distribute structured data but rather foreground the interpretative and narrative content, as "(…) *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). Other studies suggest that clinical notes containing naturalistic prose are more accurate, reliable, and understandable for clinicians reviewing medical records (Rosenbloom et al. 2010: 2). Such an interpretative stance on medical reasoning therefore emphasizes the narrative content of the medical record.

The two different logics described here produce significantly different ideas of how the medical record serves medical work. In the first logic, the medical record is typically seen as a *representation* of the patient's condition and past illness trajectory. This perspective stems from the idea that a record can appear as a passive copy that repeats an event or stores this for future reference (Berg 1996: 500). The second logic is typically associated with the point of view that the record is a "*force in itself, mediating the relations that act and work through it*" so that "*social interaction cannot be said to constitute the meaning of the medical record since the record is part and parcel of that interaction; 'social interaction is transformed through it.*" (Berg 1996: 501). Berg and Bowker (1997) furthermore

argue that the record is far from a 'post hoc *depiction of times passed and spaces explored*' and that it, rather than representing clinical facts and events, feeds into the very constitution of these.

When clinical collaboration at hospitals mostly took place within the confines of a single organization and when the information system was still a relatively organized collection of documents, the medical record served well as a tool that supported health professionals in making sense of a patient case and coordinated collaboration within clinical teams. With the increasing fragmentation of the information infrastructure in healthcare, the medical record as we know it is, however, losing its position as a central force that keeps together the many strands of chronic care. This is particularly apparent in cases of distributed care where the record is becoming increasingly insufficient as a tool to make sense of a patient's illness trajectory. Based on findings from a project aimed at designing IT support for distributed, chronic care, this article discusses how summaries in the medical record, if an appropriate balance between structure and flexibility is found, can support collaboration and sensemaking in distributed, chronic care.

Methodology

The research presented in this paper has been conducted as part of the Co-constructing IT and Healthcare (CITH) where the research group has investigated requirements for design of IT to support distributed care of patients with chronic heart arrhythmia that requires implantation of an ICD device (Implantable Cardioverter Defibrillator). ICD care involves the effort of health professionals from at least two hospitals (a specialized ICD center at a university hospital and a cardiology department at a local hospital). The overall goal of the project has been to contribute to a safe and secure life of the patients through improved communication and collaboration between all involved parties. The project has furthermore advanced the conceptual and practical understanding of how to model, develop and implement socio-technical IT solutions for communication and collaboration within heterogeneous and distributed networks of health professionals.

The project here presented has been specifically aimed at designing digital service that supports collaboration between two groups of physicians contributing to ICD care: physicians specialized within electro-physiology from the ICD center at the university hospital and physicians specialized within cardiology from a local hospital. The study had a duration of 1½ years and was conducted as a combined fieldwork and design inquiry, drawing intensively on workplace studies and the inventory of the Participatory Design toolbox. The paper is, therefore, partially based on ethnographic data and on insights that emerged through design activities.

As part of the fieldwork, we conducted semi-structured interviews with numerous health professionals from four major hospitals in the capital region of Denmark. We also conducted approximately four weeks of observations, covering referral practices, admission, physical examination, implantation, and various

types of follow-ups of ICD patients. Finally, we made in-depth studies of the main information systems in use, including medical records at two hospitals and adjacent IT systems.

The collaborative design process included five workshops with participation of five physicians from two major hospitals. Using various design techniques, including inspiration card workshops (Halskov and Dalsgaard 2006), paper mock-ups (Ehn and Kyng 1991), and generative prototyping (Cramer-Petersen 2013), an iteratively developed prototype was used to elicit requirements from the users, and incrementally design and test various properties, including the role, functionality, and interface design (Houde and Hill 1997). In between the workshops, the researchers conducted follow-up studies, and exposed the prototype to real use through field tests to challenge and develop its practical feasibility.

Software Prototype

During the project, the research team designed, developed, and tested the fully functional software prototype coSummary. This design focuses on situations where healthcare professionals need to gain an overview of a particular illness trajectory within a short period of time, e.g. when admitting a patient, at patient consultations and at rounds. The design was informed by insights from fieldwork the outcome of five co-design workshops.

coSummary is divided into an input and output screen. The input screen consists of 46 input fields (primarily multiple choice fields), sorted into five main categories. All input fields are accompanied by a comment field where the user can add additional descriptive notes. When a healthcare professional submits a finished input form, the system automatically generates the "summary" that is presented on the output screen. The output screen presents a highly condensed summary that is divided into three groups: (1) Positively confirmed information. This is the main part of the summary and shows information on the patient, e.g. core information on the heart condition, ICD device, etc. (2) Blank fields. This group contains input fields that have so far not been filled out. This may indicate factors that it may be relevant for the reader to investigate. (3) Negatively confirmed information: This group contains information that is confirmed as irrelevant. A healthcare professional may e.g. have specified that a patient does not suffer from diabetes.

While coSummary in itself represents a very detailed suggestion for a new type of summary that may support collaboration in distributed care, the prototype also served to explore the tension between structure and flexibility in new generations of medical summaries. The contribution in this paper focuses on the fundamental considerations of the role, issue, and potential for medical summaries and a sense-making tool in distributed, chronic care (Fig. 1).
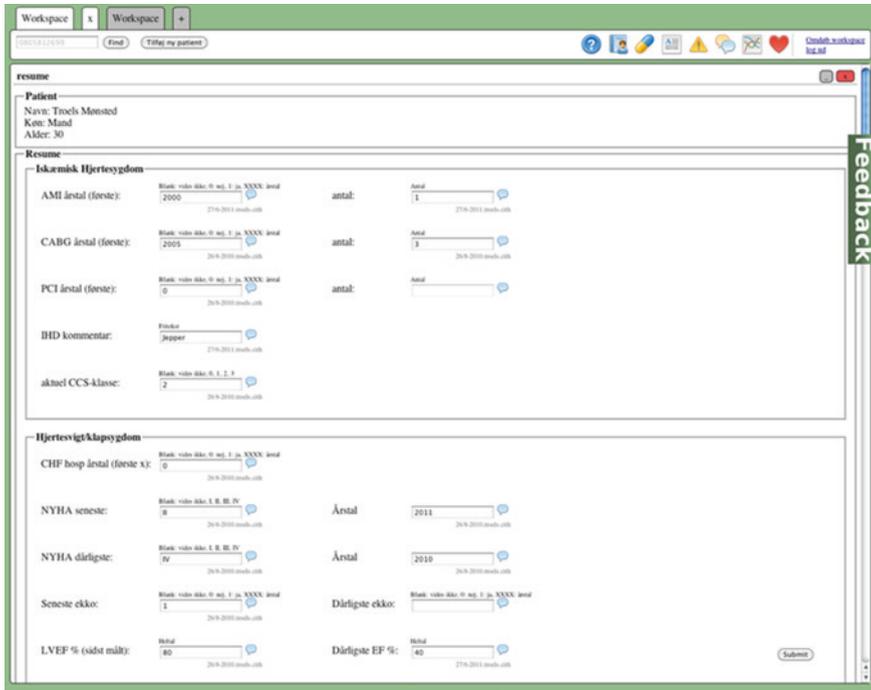
Fig. 1 coSummary input screen

A Case of Distributed Chronic Care

ICD care, while it in contrast to many other types of chronic care requires a great deal of technical expertise from patients and health professionals (Bjørn and Markussen 2013), exemplifies how chronic care can be distributed across multiple organizationally distributed care providers where the patients' are also important contributors through monitoring technology. An Implantable Cardioverter Defibrillator (ICD) is an advanced device that can automatically detect and restore normal heart rhythm in case of atrial fibrillation or heart failure. This treatment is offered to patients with chronic heart arrhythmia that cannot be treated with medicine alone. The responsibility for ICD care is overall divided between an ICD center[1] and a local hospital. Before implementation of an ICD device, a patient is most often initially diagnosed at a local hospital, either because of sustained heart arrhythmia or because the patient is admitted with acute heart failure. If physicians at the local hospital find indications that the patient meets the criteria for ICD care, the patient is referred to one of the ICD centers. Here, the patient will undergo examinations that may lead to implantation of the device (Fig. 2).

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[1]In Denmark there are a total of five ICD centers.

Fig. 2 Physician reading the medical record

After implantation, the patient will attend two types of follow-ups. One takes place at the ICD center and is referred to as the *device follow-up*. Here, health professionals monitor and assess technical aspects of the device (remaining battery level, therapies given, programming of thresholds, etc.). This takes place either at a consultation or through remote monitoring. The other follow-up is referred to as the *medical follow-up*. These take place as a consultation at the patient's local hospital. Here, a cardiologist assesses the patient's current condition and the progress of the treatment, and the aim is to adjust until a pre-defined target is reached.

A medical follow-up represents a typical situation where a medical record is in use in clinical practice, and therefore very well describes the constraints the health professionals' experience when reading the medical record. First of all, 15 min are allocated for a medical follow-up and the cardiologist is therefore rather busy completing all the necessary duties, including preparation (by reading the medical record), conducting physical examinations (e.g. blood pressure or ECG diagrams), interviewing the patient, deciding on adjustments of the treatment, and documenting his activities by dictating progress. Second, in order to perform medical reasoning well, and thereby work out how general clinical guidelines apply on the specific patient case, the physician has to position his activities in relation to a past illness trajectory and an anticipated future. Here, the physicians are, however, very challenged in keeping together information from a medical record that spreads across a range of information systems, including a paper folder, a local database (Hjerterplus), dedicated databases, e.g. Labka (laboratory tests) and www.icddata.dk (basic information about a patient's device and results from device monitoring).

Summaries in the Medical Record

> We have a nineteen hundred pages record here. I can't remember that I've seen him before. Okay. There is a note from December where we have summarized a bit. December 2008, more than a year ago. There is also a very good summary if we go back to March 2008. (cardiologist, local hospital)

While IT systems are increasingly entering the scene at hospitals, the main body of the medical record[2] at the hospitals in this study was a paper folder. This paper folder consists of a vinyl cover that holds the following documents in three pockets at the front: Cave (medical allergies), latest dispatch letter, information about referring institution, patient's ID, signed consent, and nursing notes. Inside, the content is sorted in the following categories: progress notes, cardiographic tests, paraclinical tests, ECG and holter, and dispatch letter. In total, these documents often comprise several hundred pages.

Progress notes form, so to speak, an integrative core of the medical record (Bansler et al. 2013). Physicians use progress notes to, in a very concise format, document the past medical history, current condition, clinical findings, assessments and treatment plan of a patient. Progress notes are written following each encounter with a patient. They may therefore have many different authors and may contain information about several conditions and testify different courses of treatment. In spite of the multitude of authors, progress notes follow a relatively consistent set of genre rules. For instance, the composition follows a consistent pattern whereby clinical data is documented and communicated. However, progress notes are also consistently used to express uncertainty and ambiguity, and therefore often contain an element of doubt.

Progress notes fulfill a central role for the delivery of daily clinical practice, also at medical follow-ups, and they support medical reasoning by making other health professionals' view on the patient's condition and the past illness trajectory visible to the reader. However, the strength of the progress notes, their high granularity of detail, is arguably also their weakness. As the amount of information recorded in the medical record rapidly grows, it also becomes increasingly difficult to read. The medical record has swollen to proportions that makes it hard to digest and in some cases, the medical record contains several hundred progress notes. In those situations, physicians will most often look for a more comprehensive type of progress note that is referred to as the 'summary'.

Summaries share many of the genre characteristics of progress notes (see example in Fig. 3); the language is very concise, the composition follows a relatively consistent pattern, the substance varies, and the summaries express clinical judgment, including elements of insecurity and doubt. Summaries do, however, stand out from ordinary progress notes in some important ways. First, they generally present an account of the patients' illness history in *less detail* but with

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[2]The description of the medical record and progress notes presented here is based on Bansler et al. (2013). The analysis of the summaries has not previously been published.

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Admission 08.02.07 CWARD
64-year-old male admitted for ablation. Participates in the ARISTOCRAT
project.

Allergy
Does not tolerate Propofol, caused convulsions previously. Does not tolerate
patches.

Previous
1992; stroke without residual deficit.
2000; Acute MI,
2001; CABG,

2002; PCI w stent.
Then several coronary angiograms
DC conversion x2, latest in June 2006.

Risk
Smoking through many years and in large scale, but no consumption since '00.
Increased BP, now well controlled.
Increased cholesterol, now well controlled.
No DM.
Highly predisposed for ischemic heart disease on father's side.

Present
Ischemic heart disease since 2000. Previously CABG and PCI in 2002. Coronary
angiogram several times.
Atrial fibrillation with DC-conversion 2 times, latest in August 2004. Holter
monitoring in January 2007 showed one occurrence of 3.8 seconds of non-
sustained VT and atrial fibrillation.
Occasional chest discomfort and sometimes also angina at rest and during
activity. Not certain if Nitroglycerin works on these pains. Is in NYHA cl.
2.

Other organ systems
CNS: No residual deficit after stroke in 1992.
CP: See above.
GI: No complaints.
UG: No complaints.
Extr.: Tendency to swollen legs, but not currently on diuretic treatment.
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Fig. 3 Example of a summary

emphasis on the *overview*. While ordinary progress notes are used to document observations and decisions from a single patient encounter in rich detail, e.g. a physical examination or a medical follow-up, and therefore represent a narrow, clinical gaze, summaries are used to provide overview of the broader trends in an illness trajectory. Guided by genre rules they do this in a relatively structured way, while they are still flexible enough to allow the author to express nuances. Summaries typically contain information about the patient's chief complaints, diagnosis, significant events in the past clinical history and present condition, although in and by reading the summary, a trained health professional will be able to construct a narrative of the broad aspects of the patient's illness trajectory and identify the conditions that the patient is diagnosed with or under suspicion for. Second, summaries are most often *authored infrequently*. While ordinary progress notes are entered in the medical record following all patient encounters, summaries are authored much more infrequently, not only because it is a relatively time-consuming task, but also because summaries are mainly authored to document certain events. Summaries are most often authored as *admission notes*

Medicine
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tabl. Selo-Zok 50 mg x 4 (currently paused)
tabl. Imdur 60 mg x 2
tabl. Inspra 25 mg x 1
tabl. Aspirin75 mg x 1
tabl. Apurin 300 mg x 1
tabl. Furix 40 mg x 4
tabl. Kaleoric 750 mg x 4
tabl. Marevan after schedule (currently paused)
tabl. Odrik 2 mg x 1
tabl. Akarin 20 mg x 1
tabl. Zarator 40 mg x 2
tabl. Centyl Mite 1 mg x 1
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(08.02.07)   cont....
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tabl. Rilamir 0.25 mg x 1
Nitrospray p.n.
tabl. Felden 20 mg. p.n.
tabl. Kodein 25 mg, max 2 x 4 daily.
tabl. Pinex 1 g max. x 4
tabl. Ketogan p.n.
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Objective
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Awake and relevant with good colors. No signs of cyanosis, jaundice or
anemia.
BMI Above average.in good general condition.
St.c.: Irregular heart rate = p.p. No audible murmurs.
St.p.: Ves. resp. all over. No audible rales.
Extr.: Slim and free moving. Good peripheral pulse.
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Fig. 3 (continued)

when a patient is either admitted to the hospital or transferred between wards. On some occasions, for instance in cases of complex diagnosis that require a thorough review of the past clinical history of the patient, summaries can also be authored. As a result, no formal requirements or established work practices exist, which ensure that there are recent summaries available, and often the reader will experience that the most recent one dates months or even years back. Third, summaries are *situated* in the sense that the content, while very flexible in format, is framed by a certain situation, purpose, and genre. When a summary for instance is authored upon admission of a patient, this takes place in the light of clinical findings (a diagnosis or symptoms) and the summary follows the plot of a specialized health professional (a cardiologist, oncologist, diabetologist, etc.). Thus, summaries are far from neutral representations of a past illness trajectory; rather they represent the clinical gaze of a certain medical specialism at a certain hospital. As a result, summaries both contain information that is generic, but also information that is tied up to clinical and organizational codes, e.g. abbreviations of persons, units and symptoms. Fourth, summaries are an important source of *cognitive support* in medical work that supports sensemaking. Summaries are, like narratives, far from neutral representations of past events, but an account that includes, excludes, and provides interpretation (Feldman et al. 2004). To make sense of the specific, we, however, also need to have a sense of the whole (Bruner 1991). Summaries provide this whole to the reader in two ways: First, they provide the reader with a relatively comprehensive overview of the patient's condition, as seen

from a specific clinical perspective. Second, they provide the reader with indications of what elements of the patient's condition that need to be investigated further. Thereby, summaries guide what parts of the remaining record that the physician needs to read.

Finally, summaries are *read frequently*. In contrast to the infrequent authorship, summaries are often in use at for instance medical follow-ups in ICD care. Here, physicians usually look for summaries as the first thing when preparing for a patient consultation. For the same reason, they utter frustration that the availability of such summaries is highly inconsistent. In spite of the benefit this may have on the quality of care, they are very time-consuming to produce, and health professionals often prioritize their time differently, e.g. so they can receive more patients at consultations or spend more time with the individual patient. Despite that summaries offer some cognitive support within the institutional and clinical framing from where they emerged, their role is challenged by the increased specialization and organizational distribution of chronic care.

Summaries in Distributed Chronic Care

Summaries have traditionally been widely used and fulfilled an important role in distributed ICD care. Summaries have provided health professionals with a relatively fulfilling overview of the patient's condition, past illness trajectory, previous examinations, and other conditions or comorbidities that it may be relevant to take into account. This has been achieved through a fine balance between structure and flexibility that allows them to, while remaining relatively structured and efficient to read for a trained professional, be quite expressive by documenting the patient's illness trajectory with a relatively high degree of nuance. More than being a mere representation of the patient's condition, the quality of the summaries is to be found in their ability to support health professionals in making sense of a patient's illness trajectory and providing them with clues of what to investigate further, and hereby guide reading of the medical record. This role as an important sensemaking device is, however, diminishing in distributed chronic care. This may partly be explained by the fragmentation of the information infrastructure that increases by the number of health providers involved in a course of treatment. The result is that summaries from one hospital, while accessible through an IT system (provided that the patient has given informed consent), are often not read by physicians from other hospitals. Furthermore, as substantial amounts of clinical data are stored locally at other hospitals, for instance in dedicated databases, the author of a summary rarely has full access to data on the particular patient. As a consequence, summaries often provide a less complete overview, in cases where care is distributed across multiple healthcare providers. Another more fundamental reason is that medical information does not always preserve the same meaning and connotations when it travels across organizational, professional, and personal boundaries. As argued by Reddy et al. (2001), sharing information in clinical setting is

just as much a challenge of recontextualizing this information as it is to decontextualize it, and as shown by the following case, this also applies in ICD care.

Case: How Many Electrodes Are There Supposed to Be?

As part of the CITH, we experimented with the transferability of summaries between electro-physiologists from an ICD center and cardiologists from a local hospital, both groups involved in distributed ICD care. As part of designing a new summary, we produced and experimented with a highly specialized subtract of ICD data to see how cardiologists from the local hospital made sense of this. During a test, a cardiologist from a local hospital noticed that a patient only had two electrodes (broadly referred to as *leads*) implanted and not the third LV (left ventricular) electrode. This drew his attention as the summary also stated that the patient had a CRT device implanted, which normally requires three electrodes. The cardiologist therefore concluded that the patient in fact had a CRT-D device (an ICD device with pacemaking capabilities). He suggested that the implanting physician could have forgotten either to implant the LV electrode or to record this information. An electro-physiologist from the ICD center who was also present and who implants ICDs on a regular basis, explained that they sometimes fail to implant all electrodes[3] due to complications that occur during the routine, or they choose to implant a CRT device if they assess that the patient will need the LV electrode within reasonable time, as they will then be able to reuse the CRT device. The cardiologist argued that this kind of information should appear in the ICD database, as it is otherwise confusing to him. The electro-physiologist objected, as it really is not that straightforward; what they can tell from the available data is that the device is not programmed to use the third electrode, so the patient actually has an LV electrode implanted. Or maybe the patient did not wish to have the LV electrode implanted, as this would involve open-heart surgery. The electro-physiologist furthermore explained that when information in the ICD information is ambiguous, they normally contact the operating physician. Finally, the electro-physiologist recalled that a patient from an ongoing research project had experienced sustained false therapies, probably because of a defect electrode that caused the ICD to maldetect arrhythmia. In this case, the LV electrode was therefore deactivated, which could also be the case here. This, apparently very concise, information can therefore be interpreted in different ways:

- The implantation team forgot to implant the LV electrode
- The implantation team forgot to record information about the LV electrode
- The implantation team failed to implant the LV electrode due to complications
- The implantation team chose to implant a CRT device in advance, expecting that the patient would need this within reasonable time

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[3]The device can partially function without the third electrode.

- The patient experienced a large number of inappropriate therapies, why the LV electrode had been deactivated.

As shown with this case, it can be a significant challenge for health professionals to make sense of even very specific clinical information. While this challenge of de- and re-contextualizing information is not an uncommon phenomenon in healthcare, it is expressed particularly clearly in distributed chronic care: As health professionals form new, distributed collaborative networks, information increasingly travels across traditional professional and organizational boundaries, changing the context and often the meaning and connotations of these categories. Hereby we run the risk that distributed care becomes poorly aligned, decreasing continuity of care. It is therefore of crucial importance to ensure that information included in summaries for distributed chronic care, is sufficiently meaningful for the readers.

Summaries Reconsidered

Summaries in the medical record have traditionally offered good support for medical sensemaking and collaboration in clinical teams, by enabling health professionals to provide and access an overview of the patients current condition and past illness trajectory in a relatively structured, yet flexible format. In distributed chronic care, the fragmentation of the medical record and the sheer amount information of produced have however cause the summaries to loose some of their value, mostly because they provide a less complete overview of patient information. Distribution of care furthermore complicates the use of existing types of summaries. This is partly because summaries from one hospital, while technically possible, is often not read by health professionals at other hospitals. Moreover, the meaning and connotations of clinical information is often very specialized or dependent on local standards or habits, and therefore does not always travel well across professional or organizational boundaries.

As a response to such challenges, the possibility for, either manually or automated by a computer system, aggregating data from medical records into overviews that are more easily accessed by health professionals has received great attention. As an example, the concept of *summary records* has been envisioned as an approach to assist health professionals getting an overview of patient data by providing health professional with subtracts of information from the medical record. Extending the idea of a dossier représentatif that Schneider and Wagner (1993) describe as an approach to support local practices by different, dedicated views that link to a core record, the hope is that summary records can contribute to a better, more efficient, and safer healthcare system by efficiently providing readers with a structured overview of e.g. medication, medical history, allergies, laboratory reports, referrals, and discharge letters (Greenhalgh et al. 2010). In an evaluation of an implementation of a shared electronic summary record in

England, Greenhalgh et al. (2010) found a general positive effect of summary records, not least with regard to prevention of medication errors. However, they also found that adoption was compromised by several issues, including a lack of trust in the quality of the content of the summary record and a lack of fit with existing organizational routines. Automated summary records represents a very practical approach to providing health professionals with an overview of patient data, that very well respond to the issue of time that is currently one of the causes for the irregular authoring of summaries. If such summaries are to amount to a collaborative tool that also support situated sensemaking in specialized types of distributed, chronic care, such as ICD care, I however argue that two other issues must be taken into account. First of all, the information needs of health professionals in chronic care are typically very specialized, why some elements of the patient's illness trajectory are of greater relevance for the reader than others. In the case of ICD care it is for instance important for the cardiologist to be able to access a range of key indicators for the patient's heart condition, while information on other conditions such as diabetes is of peripheral interest. Second, in order to function as a force that mediate the relations that act and work through it and thereby support health professionals in aligning their activities, and in order to support health professionals in reasoning about how the general guidelines of ICD care apply on the individual case in all of its circumstantial uncertainty, the summary should not merely be a structured representation of the patient's current and past condition, but also possess enough flexibility to allow health professionals in expressing assessments, ambiguity and doubt, as traditional summaries did.

In order to fulfill these demands, the CITH project experimented with new design principles for medical summaries in the coSummary prototype. Based on these experiences, I propose that the *readership, authorship*, and *maintenance* of summaries are reconsidered, in order to create a better fit with distributed, chronic care: First, as I have previously shown, traditional summaries are not authored with a specific *readership* in mind. Instead, they are produced as documentation of certain events, most commonly upon admission of the patient. As a result, traditional summaries typically contain a relatively broad set of information, potentially on several conditions. In contrast, coSummary was designed specifically to address the information needs that physicians have when assessing the physical condition of the patient and technical condition of the device following implantation. To address the need for accessing more nuanced considerations, all data fields in coSummary were supplemented by a free text option, in which the health professionals could add comments.

Second, with regard to *authorship*, medical summaries are traditionally written by a single health professional, typically the physician responsible for admission of the patient. This first of all frames the content of a summary, as this is shaped by the clinical gaze of this individual and is influenced by his training, experience, professional interests, genre rules in the organization and the information that is available in the medical record and the information systems at the particular hospital. Basing summaries on individual authorship, furthermore, makes it a relatively comprehensive duty, which may explain why summaries do not regularly appear

in medical records. To ensure the quality and completeness of the information presented in a summary, the design of coSummary was based on a principle of *co-authorship* whereby in principle all health professionals dealing with a patient, add information to the summary, for instance following a patient consultation.

Third, to introduce co-authorship, would also require reconsideration of the *maintenance* of summaries. A central principle that underpins current progress notes, including summaries, is that they, once written, are filed in the medical record at the hospital. Here, they are kept in chronological order among other progress notes. As the summaries are never updated, they describe the condition of the patient at a certain point in time from the perspective of the author and as the summaries (for reasons earlier described) are authored infrequently, they are not always very relevant for the reader. To increase the probability that the information in a summary is relevant and up-to-date, the coSummary prototype was designed to make it possible to maintain existing summaries, by allowing health professionals to enter new information or update existing entries when they observed change in the patient's condition. This was facilitated by a web interface that allows the health professional to easily access the editing functionality, for instance after a consultation.

Altogether, the experiences from CITH with experimenting with and testing these design principles through the coSummary prototype suggest that while it will save the health professionals little or no time when authoring a summary, the practices of keeping up-to-date and reading the summary that emerged are promising. For the health professionals, coSummary provides a very meaningful overview of a patient's heart condition which, estimated by the participating cardiologists will safe them important time that they will otherwise spend on reading progress notes in the medical record.

While the results presented in this paper is the outcome of a project dealing with care of a single chronic condition, it is important to recognize that the challenges of introducing a new generation of specialized and collaboratively authored medical summaries is further exacerbated if we take into account the general increase in the number of patients treated for multimorbidity. Multimorbidity is defined as the presence of two or more long-term conditions (either physical or mental diagnoses) in a patient and in recent years the prevalence in Denmark has increased significantly (Moth et al. 2012). As a consequence, a large fraction of patients in chronic care suffers from more than one condition. For instance, chronic heart arrhythmia is often associated with other lifestyle-related conditions, including diabetes and COPD (a severe lung disorder typically caused by smoking). Each of these conditions follow different care regimens, but as clinical guidelines generally focus on single conditions rather than combinations of disease (Boyd and Kent 2013), multimorbidity requires health professionals to actively seek information on other diseases, assess possible cross-effects of different types of therapy, and potentially prioritize these therapies, in order to avoid unwanted consequences, such as polypharmacy (Flesch and Erdman 2006). Multimorbidity therefore critically extends the challenges of designing collaborative summaries, and should therefore be taken into account in future studies.

Conclusion

In this article, I have presented findings from a project aimed at designing improved support for distributed care of patients with chronic heart arrhythmia focusing on how distributed collaboration among health professionals can be improved through IT-support. Overall, the study has revealed that summaries fulfill an important role for collaboration in clinical teams as well as for situated sensemaking. Because of a relatively structured, yet flexible format that allow health professionals to summarize patient data and pass on information with a certain level of nuance, ambiguity, and doubt. However, because of increased distribution of care and pronounced fragmentation of the medical record, the summaries are becimingly increasingly incomplete, as authors rarely have access to a full set of patient data. By experimenting with design principle for a new generation of medical summaries through the software prototype coSummary, I propose that we, to satisfy the specialized information needs of health professionals involved in distributed chronic care, engage in developing regimen-centric summaries, designed to present specialized information in a relatively high degree of detail. This however also requires that we reconsider some of the principles that underpin current summaries. By focusing the readership of summaries on members of a care regimen, introducing co-authorship of summaries and enabling ongoing maintenance, we can support health professionals in forming stronger collaborative networks across organizational boundaries, and we provide them with improved support in keeping together complex cases of distributed, chronic care.

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