

UNDERSTANDING NEEDS AND REQUIREMENTS IN APPLICATIONS FOR IDENTIFYING CLINICALLY RELEVANT SIMILARITIES BETWEEN PATIENTS WITH LIVER RELATED DISEASES

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Abstract: We present a field study at a surgical clinic of what data that is relevant in order to identify clinically relevant similarities. We have observed discussion meetings in which different medical specialities decide how to treat patients with severe diseases in the liver. Our study also includes interviews with medical personnel, and examination of two data sources, the electronic patient records and the local quality liver registry used within the clinic. Our findings include a model of data that can be useful when searching for clinically relevant similarities between patient cases, as well as requirements on the functionality of an application that can identify clinically relevant similarities.

1 INTRODUCTION

Within a highly specialised medical care in the upper abdominal tract at a hospital in Sweden, several disciplines are involved in the treatment decision of a patient. During such decision meetings, held once a week within the area of liver, it often happens that a doctor refers to a case experienced earlier. If no doctor with adequate experience is present during a meeting, or if a doctor referring to a similar case does not remember everything, information relevant for the diagnosis and treatment of the patient may be missed. This implies a need for an application where the medical information about a patient being discussed can be compared with information from earlier cases, information that could be useful.

Several studies have shown the need to uniform and structure the content of medical records. Häyrinen et al. (2008) point out that it is a challenge to standardise content and structure of medical journals, and that a clearly defined terminology and uniform information structure are essential to facilitate communication and the ability to compare data. They argue that clearly defined terms decrease the risk of misunderstandings, and that work-around terminology is a requirement of applications that can support decision making and follow-ups.

The lack of a uniform terminology makes it difficult to reuse and communicate information since one single term can have different meanings and people who use the term can mean different things (Lenz et al. 2007), which can make it difficult for health care personnel to interpret the documentation. This may increase the risk of wrong treatments.

Medical data stored in a structured way increases the possibilities for processing. Considering this, an electronic health record system (EHR) could be used for several purposes, giving secondary advantages (Britt 1995). The possibility to integrate a clinical decision support system (CDSS) with an EHR system is proposed by Porcelli & Lobach (1999).

Even though a large amount of effort has been focusing on CDSS, it appears that only a few are in use today. For a CDSS to be useful it is necessary to use an existing data source where the user does not have to manually register data for the CDSS (cf. Grudin 1988). Also, the CDSS should not replace manual decision making, but amplify and support the decision process (see, e.g., Coiera 2003).

Another important issue is to make the CDSS available at the time of the decision. O'Sullivan et al. (2007) and Johnston et al. (1994) show that by presenting the right information at the time of the decision making, doctors can be supported to base their decisions on solid grounds. They show that such real time CDSS can enhance medical care and

support efficient exchange of knowledge between different groups of medical staff.

In our work, we have focused on what data that would be relevant in an application that can compare different patient cases and present information showing similarities. We have conducted a field study of what data that are relevant in order to identify clinically relevant similarities between patients with severe liver diseases. Our study also investigates requirements on the data sources necessary in order to accomplish such comparisons.

2 BACKGROUND

Medical experts base their decisions on, e.g., existing guidelines, case studies and experiences from previous patients that are clinically similar to the current case. By developing applications that use individual patient cases as an information source including experiences from treating these patients, decision making in new cases can be supported (Rossille et al. 2005, Frize et al. 2005).

A comparison of patient cases can be based on specific data from, e.g., the electronic patient records, or on context, e.g., by indexing documented data or by rating different factors, e.g., earlier diagnosis (O'Sullivan et al. 2007). Information stored as free-text are difficult for an application to understand and interpret, but there have been attempts to use free-text index based on certain nouns and their definition in terminologies like Snomed CT (Huang et al. 2003). This requires a uniform terminology since the meaning of different terms and relations between the terms must be clearly defined. On the other hand, it can be a challenge to structure complex clinical observations and store them in forms (Hogan & Wagner 1996, Bleeker et al. 2006).

In a recent study of identifying similarities between patient cases, Melton et al. (2006) used five metrics to assess the degree of closeness between cases and to discover analogous cases. They defined similarities between patient cases by counting the differences in characteristics. They conclude that their models have the potential to be useful in the area of data mining, but that they are not yet as good as clinical experts.

In a similar study within the domain of breast cancer, Rossille et al. (2005) propose a future CDSS based on data warehouse and automatically getting similar patient cases from the EHR system. They point out that patient data today are not stored in a format proper for automatic analysis, and that the system architecture, therefore, must be decided first.

In a case based reasoning approach, Frize et al. (1996) compared and identified patient cases that are

“as similar as possible”. Documented parameters were rated, in collaboration with doctors, using special software. They conclude that this way of using experiences from earlier treated patients can enhance patient handling in intensive care units.

These studies imply that an application that can identify similarities between patient cases has the potential to be helpful in medical care. Also, these earlier studies point out the importance of using uniform and structured data and terminology.

In order to understand the conditions for such an application, we have conducted a field study at a surgical clinic at a hospital in Sweden (Gastro). We have identified what data that are relevant to compare, and examined the possibilities to use documented information as data sources.

3 METHODS AND THE SETTING

Our research is based on close interdisciplinary collaboration between researchers within the fields of human-computer interaction, medical informatics, and surgery. We have used qualitative methods and based our work on grounded theory. The data collection has been made through interviews, observations, samples of medical records, and examination of a local quality liver registry. In total seven interviews have been conducted with liver surgeons, a radiologist, a terminologist and a medically trained doctor working with IT solutions. Observations have been conducted of eight multi-disciplinary video-mediated liver meetings, in which decisions about how to treat the patients are made. All interviews and observations have been recorded and transcribed or documented with field notes (two observations). Twelve samples of anonymised electronic patient records from the liver decision meeting have been analysed.

Multi-disciplinary video-mediated meetings are held at Gastro every week within the area of liver. The discussion during these meetings may identify unclear issues that need to be further investigated, focus on results from samples made and so forth, all in order to come to a consensus about the best possible treatment. Each patient case discussion follows the same structure with a clinical presentation of the patient, a walkthrough of the radiological examinations, and a discussion of how the patient can and should be treated.

Gastro uses an EHR system (hereafter named TC), that supports the whole care process, and to document different care related activities there are different kinds of notes. These notes can, to a certain degree, be structured by using common headlines. The headlines have to be defined in a catalogue of terms associated with the system, to make it possible to search for the terms in free-text. By structuring

notes based on already defined terms the uniformity between patient records increases.

The decision made at each liver meeting is documented using specific notes in TC, summarising the patient's condition, results and interpretations of radiology pictures, the decision made and the plan of how the decision should be fulfilled.

Gastro also uses a local liver registry, which includes information about all patients with tumours in the liver, gall bladder and biliary passages, and who has been treated with surgery. Data in the liver registry is registered using a form based input and consists of parts of the information that is stored in TC, but in a more structured way. There is also information in the liver registry that has not been documented in TC.

4 RESULTS

4.1 Description of Patient Cases

Our observations of the liver meetings show that the same categories of data, to a large extent, are in focus during the discussions:

- patient status, e.g., age, motivation, weight, general health, and strength,
- subjective symptoms, e.g., gastrointestinal symptoms and tumour symptoms,
- present disease, e.g., diagnosis, judgements, treatments, progress,
- present and earlier diseases and treatments,
- status of the liver, e.g., the function,
- examinations made and their results, e.g., radiological examinations, laboratory tests, and function tests,
- implemented and suggested actions, e.g., treatments and planned examinations.

When examining the documented notes in TC from the decision meetings, we found that they mainly included the categories subjective symptoms, examinations made and their results, and implemented and suggested actions. The most significant difference found was that the information in the medical records is not as detailed as in the discussion during the liver meetings.

Examination of the liver registry indicates a similar content, but structured using some other categories:

- patient status, e.g., sex, length, weight, BMI,
- subjective symptoms, e.g., tumour symptoms,
- status of the liver, e.g., the function,
- examinations made and their results,
- tumour information, e.g., type and size,
- treatments.

The category "treatments", contains data that can be found in the category "implemented and suggested actions" from the liver discussions. Also, "tumour information" is a more specific category, but is included in the category "present disease" from the liver discussions.

Interviews with clinically working doctors gave an understanding of what data about a patient they find relevant to compare to identify clinically relevant similarities. Two of the surgeons said:

Unni: It is how old the patient is, the condition, earlier illness, liver function, if the patient have had earlier liver diseases, present values of the liver function /.../ other kinds of diseases, diagnosis and how long the disease has proceeded.

Bill: It can be plenty, anatomic variations, tumour growth in different ways, how often we manage to do a resection, how often we can accomplish an R0, a radical situation. It can be a case where we have ten liver metastases that are located a couple of centimetres deep, and we want to make local resections. Then you get a feeling that this is not good, we will not accomplish an R0-situation because we seldom do. Today, we do not have that kind of structured documentation that can confirm these suspicions.

What is interesting is that the two surgeons stress the level of detail that often is missing from the medical records, e.g., how the tumour is growing, how long the disease has proceeded, and how the tumours are located. They also mention other diseases as relevant, i.e. comorbidity.

During the interviews we also asked what data in general that are needed at the liver meetings to make a good decision about the treatment. From the answers it is obvious that there are specific kinds of data that are relevant for the decision, but that the surgeons do not find relevant when searching for similarities different patient cases:

Bill: It is data about how ill the patient is, how he or she can manage the treatment, how motivated the patient is to different kinds of treatment. Then it is all the details about the oncology treatment, how the patient has responded to that treatment. That [kind of information] is sometimes poorly documented.

Hence, from the interviews the following categories have been identified as relevant content:

- patient status, e.g. age, motivation, general health, and strength,
- present disease, e.g. diagnosis and how long the disease has proceeded,
- status of the liver, e.g., the function,

- examination results, e.g. describing attributes of the present disease such as anatomic variation and localization,
- implemented treatments and results,
- comorbidity and earlier diseases.

The examination results appear to be an important source of information when identifying clinically relevant similarities. Therefore, we have focused on relevant examinations including treatments and diseases (e.g., comorbidity and primary disease), e.g., radiological examinations, laboratory test, biopsies, endoscopic examinations, functional tests of organs, and clinical judgements. These examinations appear to generate the same kind of information expressed in different ways. One such example is the function of the liver, where there are laboratory tests that can measure levels of certain elements in the blood, e.g., ASAT, ALAT, ALP, albumin, PK, bilirubin. Also, radiological examinations can, to some extent, show the liver function, e.g., signs of cirrhosis. There are also functional tests that can be used to describe the function of the liver, e.g., ICG-clearance values and elastographic imaging.

4.2 User Needs and Requirements

Another focus in our work has been the doctors' needs and requirements of an application that can identify clinically relevant similarities between patient cases. During the interviews, the clinically working doctors had, mainly, a positive attitude towards such an application. To exemplify what is expected, let us take an example from one of the interviews, in which Joe, a senior surgeon and manager, said:

All these [radiological examinations and data about the patient's medical history], the discussion and the conclusions made, that they in the specific moment, at the same time as they are generated, can be collected in a database. That the database thereafter can recognise, based on a pattern, /.../ that five patient cases look similar and are presented.

Responses from the doctors were that such an application should support and facilitate experienced based care and decision making, needs to be carefully designed, is useful only if the similarity measures are specific enough and clinically relevant, and can be useful during the liver meetings when there is an uncertain patient case. Bill even said that he thinks it could be worthwhile an extra effort of entering information into such a system if it could prove to be useful (cf. Grudin 1988).

However, all surgeons were not equally positive. Unni thought that this kind of system could mainly be useful for doctors with less experience:

It is not obvious [how such a system can be useful] because of the way we work, with the contacts we have, attending congresses and so forth. We keep ourselves updated and we have a large volume [with patients]. I think we work pretty much like such a system without having to use it. Such a system feels like a cookbook for people that are not as experienced, and that can be interesting, but I don't think it would be useful for me. It takes a lot of effort to build it [to fill it with data and keep it updated].

We have also observed several liver meetings in which associations to similar patient cases were made in the discussions. The surgeons interviewed responded that similar patient cases that today come up in a discussion as a reference case are helpful for a decision in the present case. However, such references are dependant on the medical doctors present during the meeting, and they are usually quite weak since the doctors are not always able to recall all details. Sam, a meeting participant said:

We have had a similar case earlier, exactly the same CT. /.../ We have the answer but I cannot remember exactly.

Nora, a radiologist said in the interview that she had worked with a similar application, in which similarities were based on registration of ten codes per patient, but that the similarities were not specific enough. She found such an application useful, if the similarities are more specific and detailed.

When asking Bill in what situations such an application could be useful he said:

It is in those cases that are uncertain, for example if we should do an operation or not. In many cases it can be questioned if it is meaningful to do an operation from a tumour biological approach. If we had a fine grained database that could show the results of these kinds of patients.

It appears that the granularity of the data that are compared and that are presented from similar cases is an important aspect for success.

4.3 Documentation Routines

One important part in this kind of application is the existing routines and the doctors' attitude towards documentation and changes of documentation routines, including the terminology used.

All doctors interviewed agreed that the terminology is important in the medical work. Some

said that they are careful how they express themselves, to avoid misunderstandings. They are aware of a certain degree of shifting in the terminology used, but think that misunderstandings are rare since the situation provides a context for the understanding. They said that each doctor has her own way of expressing herself, but the use of terms should not be restricted. Jim, a senior surgeon, said that what terms that are used and how they are used is a negotiation based on different aspects:

It is not that you try to talk using the terms defined in TC. Instead the terms in TC needs to be adapted to how people express themselves. Then, of course, when you document you still need to adapt [to the term catalogue in TC], everybody can't express themselves as they want and all terms can't exist. The goal with the terms is that you can use them to search.

In TC there is a term catalogue that can be used to increase the ability to search and unify the documentation. However, the interviewed surgeons found this work somewhat complicated because of a lack of administrative routines for defining new terms, both on a clinic and hospital level. Earlier attempts to apply for new terms to be added to the term catalogue had no result. The surgeons are also unaware of new centralised efforts of a terminologist, i.e., their attempts to work with terminology issues have been down prioritised.

After the liver meetings each decision is documented in TC. The decision note is not a formalised structure in TC, but it follows a template with headings such as decision and activity, how to carry out the activity, major diagnosis, and whether the decision involves operation or not. The formalised way of doing this would be to use the term catalogue to build the structure inside TC. Bill said that in the beginning he found the template for the decision documentation too structured, but now he would like it to be more structured. He would like the decision itself to be documented in more detail, not only suggesting one alternative, but also why other alternatives have been rejected. Bill also said that one reason why this often is missing could be that the surgeon documenting the decision is usually not so experienced and, therefore, may not have followed the whole discussion.

The local liver registry and TC consist, to a large extent, on the same kind of information. The main difference is that the documentation in TC is more specific and detailed, but the liver registry contains some specific parameters for statistical analysis, e.g., the amount of bleeding during the operation, if the circulation was turned off to the liver during the operation, how the liver was cut, how much of the

liver that was removed, and what kind of operation that was made. About the liver registry, Bill said:

It is that kind of data that you want to use to learn for the future, what patients that can manage a turndown of the vessels or not. These kinds of things are never documented in TC. /.../ There is usually an operation documentation, but in the best case the operation code coincides with what was actually done.

5 DISCUSSION

Based on our observations, interviews and investigations of documentation in TC and the liver registry, we identified five categories of information that can be relevant when identifying clinically relevant similarities between liver patients:

- *General Data about the Patient*, including general health and strength, age, function of other organs, and clinical assessment.
- *Data about the Liver Function*, including laboratory tests, examinations of the liver function, and comorbidity concerning the liver.
- *Data about the Present Disease*, including radiological examinations describing the type of examination, contrast load, position and size of affected tissue, and relationships to large blood vessels and biliary passages, laboratory tests, biopsies, and diagnosis.
- *Data about the History of Diseases*, including a documented history of diseases with diagnose, spread of disease and point of time.
- *Data about Treatments*, including point of time, kind of treatment, and effect.

The above presented data model is based on information that is documented in TC and the liver registry, but origins from mainly three sources: examinations, documented medical history including earlier examinations, treatments and diseases, and the patient's subjective description of the symptoms, motivation, disease history and so forth.

One consideration regarding the data model concerns the validity of different data, e.g., the documented symptoms, which are dependent on the patient's communication ability. This results in a subjectivity, which makes comparisons of symptoms unreliable. Symptoms were not mentioned by the doctors during the interviews, but were frequently discussed during the observed liver meetings. Although symptoms can give important information about the disease and possible treatments, we have chosen not to include such data in the proposed data model because of this uncertainty and subjectivity.

One interesting question concerns how the data of

interest can be found and should be described. We have shown that there are several alternatives used to describe the same kind of information. To make it possible to compare data, it must either be documented in the same format and/or using the same terms, or it must be possible to use a translator between the different formats and/or terms.

During the interviews the radiologists expressed that they are careful in how they express themselves, both during the meetings and when documenting the examination. If they say that they are *certain* that the dark change on the CT is a tumour, then they are. Otherwise, they say that it *appears to be* or *behaves like* a tumour. It is a relevant difference between a *certain tumour* and a *likely tumour* and an application should be able to understand such difference. The question is how the level of uncertainty can be used when searching for similarities. One solution could be to use same kind of rating variables, but needs to be further examined.

Also, the level of detail in content is important to make the application useful for experienced doctors. If the data is not detailed enough, it will not identify similarities on the right level.

6 CONCLUSIONS

We have focused on what data that would be relevant in an application that can compare different patient cases and present information showing similarities. This is only part of a broader perspective, including not only data but also information from different kinds of media.

The aim of such an application would be to create a kind of “clinical binocular” that can focus on the right information at specific moments. It should not only cover for situations when the right experience is missing, but also for situations when a doctor may not fully remember the previous case or when individual interpretations previous cases influences what is remembered. In some sense it should strengthen the “clinical eye”.

It is also of interest to keep in mind that the functionality of such an application affects the content of the data sources, i.e., it needs to be detailed, searchable, and structured. This, in turn, affects how the documentation is made, something that may require changes in documentation activities and routines. Two important issues have been pointed out during the interviews: the effort to make changes must be rewarded and give a clear surplus value, and the changes must be easy to implement with helpful assistance and aid that reduce the doctors’ efforts.

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