Get the Right Balance – Lessons Learned from the First Ebola Infected Patient in Dallas

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For over a year the Ebola outbreak in West Africa is one of the most important issues. This was a great challenge for the affected regions and demonstrated by the first Ebola patient at the Presbyterian Hospital in Dallas in October 2014 [1, 2]: A 42-year-old man showed up at the emergency department with unspecific symptoms and was sent home with the diagnosis ‘sinusitis’. The patient returned three days later, a test confirmed the Ebola virus and he died in isolation at the hospital 10 days after starting therapy. During this time, two nurses were infected by the virus.

When looking for a responsible person, the answer was quickly found: The Electronic Health Record (EHR) [1, 3]: Why did the software not make the doctor aware that the patient with fever was previously in West Africa and could therefore potentially be infected with Ebola? The question is so simple from the user’s perspective, but the answer is a complex one.

The first condition is that an EHR is only able to present information if the information is present. For this purpose, it has to be entered (by someone else). Several studies have shown that medical records are not complete. The best completeness is achieved in the area of medication prescription data, followed by automatically imported data (e.g. laboratory results) and diagnoses [4, 5, 7, 8]. Normally, it is not possible to distinguish, whether a symptom is not examined and therefore not documented or whether the patient does not have this symptom. This might be improved by completeness checks in the EHR. Although it is impossible to capture all information from all patients. There is a need for an EHR system to support users to capture all relevant data of a patient. Therefore, “Completeness […] is contextual and determined through an understanding of specific data needs” [8]. Therefore, completeness checks must be implemented depending on context to avoid unnecessary information and work. Context-dependent checks require a rule base, when and what information is relevant to make a decision or when it is needed for a process step. Even if such a rule base is available, it remains a challenge, that too frequently used completeness checks increase the workload and thus decrease the motivation to enter valid information. It is a challenge to find the optimal balance between mandatory and optional documentation.

The second condition is that the data must be computable. This means that the data has to be structured and that they are semantically annotated captured and stored; the only way to ensure that the information can be retrieved and properly interpreted by a machine. In most cases, records and forms are structured so that the fields are clearly defined, but the contents are recorded as free text. (This corresponds to HL7 CDA Level 2.) This limits the interpretability of data, for example for the automatic generation of reminders and notifications or alerts. A safe interpretation of the documented patient data needs the use of controlled vocabulary as possible using standard terminologies, nomenclatures or classifications. (This corresponds to HL7 CDA Level 3.) Particularly in the case of the use of classification, this results in a loss of information (details). It is a challenge to find the optimal balance between the need for computable annotated parameters and the need for sufficiently detailed information (commentary fields, free text fields).

The third condition is that a computer must be able to anticipate, which information is needed in a specific situation. This requires a distinction between the known and the unknown ignorance. The case of known ignorance can be solved easier:
In the case of potentially Ebola infected patients, a physician may ask the patients directly about their travels during the last few weeks. Although a physician could look at the EHR, the EHR is actually not necessary in this case. In the case of unknown ignorance the computer must know, which information is relevant for the next decision or for the next process step. The more information that is collected and stored on the patient in the EHR, the more difficult the decision is when and what information should be indicated. It is impossible to display all the information and it is impossible for a user to read all the information. It threatens an information-overflow or an alert-fatigue. Therefore we need user interfaces with good suitability to such a task. It is a challenge to find the optimal balance between the completeness of directly offered information, notification and alerts on one side and information and workload reduction on the other.

The fourth condition is that a system, proactively deciding about the context-relevance of information must function reliably. If a system regularly gives relevant information to a user, then the user will trust the system and will rely on it. Such an EHR system thereby changes user behavior and takes responsibility. So our ability to remember may worsen, unless they are safely stored and handled [6]. An active support by displaying relevant information is especially required for rare diseases. Even in systems with good discrimination (sensitivity and specificity) for detecting the disease or situation the prediction quality (positive and negative predictive values) for rare events decreases. The only way out is to inform the user about the limitation of a system and to transfer liability to her or him. It is a challenge to find an optimal balance between reliability of the system and the responsibility of the user.

The fifth condition is sustainability and economic efficiency of a system. Therefore, rare events especially have to be covered by a rule base. This leads to an extremely high effort, which is also described by the Pareto principle: Most patients will always need the same information and rules, and few patients require different information and rules, then in extended form. Because of limited resources in health systems, it is a challenge to find the right balance between risk reduction and patient safety on one hand and optimal use of resources on the other.

Conclusion: The Presbyterian Hospital Dallas deserves our respect that they have withdrawn the allegations against their EHR system very quickly and reported self-criticism about their experience and their lessons learned [2]. It is a task for medical
informatics to provide methods, finding an optimal balance in design and usage of an EHR – and to discuss what is possible and what is feasible.

References


