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Evaluation of a Hyperlinked Consumer Health Dictionary for Reading EHR Notes

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Abstract. In this paper, we report on a pilot study conducted to test the usefulness and understandability of definitions in a Consumer Health Dictionary (IVS-CHD). Our two main goals for this study were to evaluate functionality of the dictionary when embedded in electronic health records (EHR) and determine the methodology for our larger-scale project to iteratively develop the IVS-CHD. The hyperlinked IVS-CHD was made available to thoracic surgery patients reading their own EHR. We asked patients to rate definitions on two 5-level Likert items measuring perceived usefulness and understandability. We also captured the terms that patients wanted defined, but that were not included in the IVS-CHD. Preliminary results indicate the types of problems that must be avoided when creating definitions, for example, that patients prefer detailed explanations that include medical outcomes, and that do not use "unfamiliar" terms they must also look up. We also have gained insight into the types of terms that patients want defined from their EHR notes, especially certain abbreviations. Patients further commented on the experience of reading EHR notes directly from the same system used by healthcare personnel and the help strategy of linking the contents to a hyperlinked dictionary.

Keywords. Consumer Health Information, Dictionary, Electronic Health Records

1. Introduction

Health records are internal working documentation used by healthcare professionals, and are also official legal documents. Until recently, patients' ability to understand and use the contents of these records has not been a huge concern. Yet now, with more countries passing legislation giving patients legal right to access their records and increasing availability of personal health records systems, many researchers are working on ways to help patients understand their health record content [1-3].

The Intervention Centre (IVS), a multi-disciplinary research centre at Oslo University Hospital (Rikshospitalet) in Oslo, Norway, has developed a consumer health dictionary (IVS-CHD), which is accessible through hyperlinks and embedded in the electronic health records (EHR) used in the hospital. Patients reading their records see, for example, their surgical notes with hyperlinked terms throughout the text. When mousing over a hyperlinked term, definitions are displayed in a pop-up box. At the bottom of the pop-up box, other links can be found that take the reader to further

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information, opening a new web browser window with the contents. The IVS-CHD resources include the patient version of a Norwegian catalog of pharmaceuticals with the detailed drug descriptions [4] and an encyclopedia of medical information that was written for patients [5]. The encyclopedia contains textual information in addition to diagrams, Flash programs, videos, and animations. The third source was the Norwegian Medical Dictionary (Norsk Medisinsk Ordbok) published by Kunnskapsforlaget [6].

Our primary task is the evaluation of IVS-CHD definitions for use by patients and the general usefulness of the embedded consumer health dictionary tool. We report on our study that is seen as a preparation for further work to iteratively improve the patient-friendly definitions of medical terms. The concerns we address are:

- Is our consumer health dictionary seen as a useful explanatory tool for patients that will help them understand their own record content?
- What makes a good definition for patients? Patients are not one heterogeneous group. How do we write good definitions for everyone?
- When patients read their records, what do they really want help with? Which words do they want to look up and why?

2. Methodology

We evaluated the IVS-CHD using patients from the thoracic surgery department at Oslo University Hospital (Rikshospitalet). These patients are referred to the hospital from all regions in Norway and may live in either an urban or rural area in the country. Through our interactions with these patients, we iteratively developed the methodology that will be used in the larger-scale research project.

2.1. Participants

The five participants in this study were outpatients at the thoracic surgery unit. All the patients were male and between the ages of 58-68, having diagnostic codes related to cardiac transplant, carotid artery stenosis, or myocardial infarction. Their occupational backgrounds were diverse. They all came for tests and preparatory work in advance of an upcoming scheduled surgery. Patients were asked to participate as they became available, over a two-week period in December of 2010. Patients had to fulfill the selection criteria before they were asked to participate: (1) the patient must have had at least one prior surgery at the hospital so that there would be a previous history of notes for the patient to read, (2) the patient must be a native speaker of Norwegian, (3) the patient must be able to read/write in Norwegian, and (4) the patient must have normal cognitive functions (i.e. no stroke patients or known cognitive impairments).

2.2. The IVS-CHD Consumer Health Dictionary

As stated above, the definitions displayed when patients mouseover EHR text come from several sources, which are merged in the IVS-CHD. Surgeons affiliated with IVS wrote some of the definitions. They were only instructed to create a definition that would be understandable to patients. We cannot be certain of the rules used for forming definitions in the drug handbook [4] or the encyclopedia (NEL) [5]. For the Norwegian medical dictionary [6], the editor has written that “definitions should not contain words

that cannot be found elsewhere in the dictionary, and they should be built up hierarchically so that the concept group the word belongs to (medicine, disease, muscle clip, etc.) is the first thing explained, and only after that the specifics for the word." [7] Definitions in the Norwegian medical dictionary [6] are often preceded by explanatory synonyms.

2.3. Procedures

The total time allocated for each patient was 45 minutes, and this was the maximum possible due to constraints such as staffing time and convenience for the patients. The patients were tested in a private room with two researchers and a nurse present. They used a laptop to read their own records directly within the hospital's EHR. All patients were explained the purpose of the study and signed a consent form prior to completing study tasks.

Task 1, Rate Definitions: The patient selects a part of the record from the doctor's notes, nursing notes, surgical notes, or discharge summary- the entire record is available so the patient chooses what is of interest to them. All terms in the EHR text having definitions in the IVS-CHD are displayed using standard blue hyperlinks. When a patient clicks on a hyperlink, we automatically record that the term has been accessed. After reading a definition, the patient then rates the definition on two 5-level Likert items. They are: 1) the usefulness of the definition is not useful/useful, and 2) understanding the definition is difficult/easy. In addition to the rating, the patient's comments about the definition are recorded. There can be more than one definition for a term available (since there are combined sources, e.g. one definition written by surgeons and one from the Norwegian medical dictionary). The patient must give ratings and comment on each definition.

Task 2, Complete Brief Questionnaire: The patient answers the following questions: (1) Do they wish to read their EHR notes: on paper, on screen, or no preference? (2) What can be done to make the records easier to read? (3) How can the EHR be improved to make it easier for patients to understand?

Task 3, Underline Difficult Medical Terms: Patients read a printed copy of the discharge summary from their last thoracic surgical procedure at the hospital. Terms are not underlined as they were on-screen using the IVS-CHD functionality. The patients are then asked to read and underline for themselves the terms that they feel are necessary to have defined. We do this in order to find out what terms need to be defined that are not yet in the dictionary.

3. Results

There were 5 patients participating and together they rated a total of 25 definitions. We were able to capture some aspects of the types of definitions thoracic surgery patients prefer to have and terms that they need defined, though the small sample-size is a limitation of the current study.

3.1. Definitions

The definitions written by the published medical dictionaries did not fair any better than those written by the surgeons from our hospital. Problems and desiderata are described in Table 1.

Table 1. Lessons Learned From Problematic Definitions.

Defining Medical Terms for Thoracic Surgery Patients: Lessons Learned
(1) Do not use unfamiliar medical terms within the definition that also need to be looked up. e.g. **vertebral artery*** - an artery that arises from the subclavian artery supplying the brain with blood (translation of: **arteria vertebralis** - arterie som avgår fra arteria subclavia og forsyner hjernen med blod) **written by surgeons* (2) Make sure the definition is complete. Definitions need to fit in the context of the patient's situation and must therefore include the necessary information for understanding what happened during a procedure. e.g. **thoractomy**[6] - surgical opening of the chest (translation of: **torakotomi** - kirurgisk åpning av brystkassen) should contain additional information about approach: sternotomy, posterolateral, and anterolateral. (3) Avoid single word definitions.e.g. **dilation**[5] - expansion (translation of: **dilatasjon** utvidelse) (4) Avoid circular definitions and definitions that are based on the same term but in a different grammatical form; instead go straight to the needed clarification. e.g. palpatory[6] - has to do with palpation (translation of: **palpatorisk -** som har å gjøre med palpasjon) (5) When possible, write definitions that explain effects. Explanation is crucial to patients who prefer outcome information. e.g. A definition rated highly by a patient: **TIA**[5] - "transient ischemic attack" transient decreased blood flow to part of the brain with transient loss of body or mental functions, the condition clears within 24 hours (translation of: **TIA** - "transitorisk iskemisk atakk", forbigående nedsatt blodstrøm til en del av hjernen og med forbigående tap av kropps- eller mentalfunksjoner, tilstanden normaliserer seg i løpet av 24 timer) e.g. A definition given a low rating by a patient: TIA[6] - transient ischemic attack, transient bouts of oxygen deprivation in parts of the brain (translation of: **TIA -** transitorisk ischemisk attakk, forbigående anfall av oksygenmangel i deler av hjernen.)

3.2. Terms to Define

Below in Table 2, we present an example list of terms that patients accessed in the IVS-CHD while reading their notes related to thoracic surgery, and also those terms in the records they want included in the dictionary in the future.

Table 2. Examples of Terms Patients Want in the IVS-CHD to Help With Understanding Their EHR Notes

Examples of Terms Accessed in IVS-CHD	**Terms to Include in the IVS-CHD**
opiates (opiater)	poststenotic (post stenotisk)
carotid stenosis (carotisstenoser)	coartation (coorctasjon- misspelling of coartation)
abdominal aortic aneurism (abdominalt aorta aneurisme)	
doppler (shortened version of doppler heart monitor)	
BT (abbreviation of blood pressure in Norwegian)	
SPO2 (abbreviation of oxygen saturation level)	
intercurrent (interkurrente)	
cardiopulmonary (kardiopulmonale)	
central obesity (sentral adipositas)	
abdomen (abdomen)	

Patients want to be able to see expanded versions of all the shortened expressions and abbreviations in their EHR. The IVS-CHD currently has limited ability to identify abbreviations and acronyms. It identifies acronyms with several meanings, but does not have context-sensitivity built-in and therefore displays all possible meanings to the patient. The thoracic surgery patients did not seem disturbed by this and were able to identify the correct definition themselves.

3.3. General Comments and Usefulness of the IVS-CHD for Reading EHR Records

We recorded the comments concerning reading of EHR surgical notes and the use of the IVS-CHD. Overall, patients regarded the IVS-CHD positively, and thought it would be useful for themselves as well as for non-specialist healthcare personnel. One of the patients said he was expecting a "translation" and would prefer to receive a different patient-oriented version of his discharge summary. Another clearly voiced that "I'm not interested in learning", meaning that he did not want to learn the anatomy, procedure, etc. connected to his own surgical procedure. It was the outcome and future treatment plans that he wanted. Another said that he wanted the definitions to be personalized with examples from his own records. Lastly, one of the patients stressed that terms having the potential to be misunderstood should be defined in the IVS-CHD, such as "negative" test result. This patient said, "at first I thought it meant that the test result was bad", but then was relieved to know that having a negative result is actually a very good thing. This statement confirms a finding in Keselman et al. [2]

4. Discussion

Difficulties that patients experience with medical terminology have been studied extensively. The primary tools that have been developed to help alleviate these problems are consumer health vocabularies (CHV) [e.g. 8,9]. CHV's can be used within information systems in a variety of ways, but they are primarily intended to automatically replace "unfriendly" professional terms with terms that are considered more appropriate for patients, thereby changing the text to a simpler version [1]. Our approach is to provide easily accessible definitions to patients reading their EHR rather than "translating" the text to a patient-friendly version. This is similar to SciReader [10], which is another tool to read medical content with instantaneous definitions. In this pilot study, we have taken a step forward to evaluate this type of proposed aid to understanding. Understanding what terms patients want defined and how to write useful consumer-oriented definitions is a problem to be addressed. Future studies will focus on patients' needs for dictionary resources versus translated versions of EHR content.

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