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A Usability Study of Patient-friendly Terminology in an EMR System

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Abstract

Misunderstandings due to terminology differences between health care providers and consumers may cause communication problems and adversely affect consumer access to health information, resulting in poor satisfaction for patients and providers. To investigate the usage patterns of consumer health vocabulary and evaluate controlled terminologies used in electronic medical records, we *conducted a usability study of patient-friendly terms used in an ambulatory electronic medical record (EMR) and associated patient web portal. After identifying 340 unique diagnosis term / patient- friendly term pairs, we mapped the term pairs determined by UMLS to be pairs of synonyms, near-synonyms, or closely-related terms to the keywords of search queries extracted from a consumer health information web portal to learn the comparative frequency of use of members of each pair by consumers. We found out that use of patient-friendly terms could help to bridge the language gap between providers and consumers but not always. In some cases the professional diagnosis terms were used more frequently than their patient-friendly counterparts, typically in cases where the professional terms were more simple or common than the patient-friendly terms.*

Keywords:

Terminology, Medical records, Internet, Patient access to records, Unified Medical Language System.

Introduction

There is a language gap between health care providers and consumers. Providers may not always familiar with medical terminology used by consumers. Likewise, consumers may not know the terminology used by providers. Misunderstandings due to terminology differences may cause communication problems and adversely affect consumer access to health information, resulting in poor satisfaction for patients and providers.

The differences between patients' and providers' expressions of medical concepts have long been recognized and studied [1-5]. The language gap between health care providers and consumers affecting health information retrieval has been studied in the fields of informatics [6-9]. Previous studies have demonstrated needs and efforts for bridging the language gap by developing consumer-friendly terminologies [10-18].

Zeng's research group has developed an open access and collaborative consumer health vocabulary initiative project. They identified 753 consumer terms and found the logistic regression model to be highly effective for term identification in strings derived from query logs of a consumer health site. In Zeng's logistic regression model, frequency of occurrence, string length, word count and number, frequency and termhood status, and nested strings are primarily used as variables, and the master vote as outcome[19]. In their previous study, Zeng's group developed a systematic methodology using corpus-based text analysis followed by human review to assign "consumer-friendly display names" to medical concepts from the UMLS Metathesaurus [20].

Plovnick and Zeng investigated the effect of reformulating consumer health queries using professional terminology [21]. They further developed a query suggestion tool called Health Information Query Assistant system to help consumers search for online health information. The system suggests alternative/additional query terms related to the user's initial query that can be used as building blocks to construct a better, more specific query [22].

Zhang and other researchers used a multidimensional scaling information visualization approach to examine user log files from a consumer health information web portal HealthLink. They investigated query searching behaviors and visually revealed groups of frequently used medical terms, and provided insight into semantic relationships among them [23]. Zhang's research group further employed an information visualization technique Self-Organizing Map (SOM) in combination with a new U-matrix algorithm to analyze health subject clusters through the HealthLink transaction log, which leads to a better understanding of the health-related topics and terminology from the users' traversal perspective [24]. While previous studies examined consumer-professional terminology difference either in health information retrieval or in the medical record, in our study we have explored the influences of the language gap in both areas and focused on the use of consumer terminology in an ambulatory EMR.

Since 2004, Froedtert Hospital and the Medical College of Wisconsin (MCW) have implemented an ambulatory electronic medical record EpicCare Ambulatory (Epic Systems Corporation, Madison WI). In 2008, an associated patient web portal MyChart® was implemented. MyChart® is the shared patient electronic health record integrated with the EpicCare Ambula-

tory EMR used by the healthcare team at Froedtert & MCW clinics. It gives patients controlled access to portions of their electronic medical record.

The EpicCare Ambulatory EMR incorporates a third-party medical vocabulary lexicon called Problem (IT)™ (Intelligent Medical Objects (IMO), Chicago, IL) Problem (IT)™ is a clinical diagnosis and problem list vocabulary containing specialized terms for clinicians, coders, and patients that links to ICD-9-CM. This lexicon enables an ICD-9-based controlled vocabulary to represent the descriptions that clinicians use when documenting diagnoses on the problems lists, or past medical history. Patient-friendly terms incorporated into Problem (IT) ™ are specifically designed for patient web portals like MyChart®. For example, a clinician may enter the clinical term 'Otorrhea' on a patients' problem list without needing to know the exact ICD-9 term or code (Unspecified Otorrhea 388.60). Likewise, a coder familiar with the ICD-9 code or term can specify either and locate the correct diagnosis. In EpicCare, providers can review and update the patients' problem list with clinical terms mapped via the IMO Lexicon. In MyChart®, patients see the patient-friendly terms associated with the diagnosis. In the previous example, when a clinician adds 'Otorrhea' to the problem list, the patient will see the associated patient-friendly terminology 'Drainage from the ear' in MyChart®. Quite often, the clinical term on the problem list is different than the patient-friendly terminology. These differences can lead to misinterpretations and confusion for both the patient and the provider, and can affect the quality of physician-patient interaction.

To investigate the usage patterns of consumer health vocabulary and evaluate controlled terminologies used in electronic medical records, we conducted a usability study of patient-friendly terms used in the EpicCare Ambulatory and MyChart®.

The study is significant because it:

1. Explores the different ways health care providers and consumers apprehend and express health concepts;
2. May improve communication between health care providers and consumers, assists consumers to better understand their health issues and helps them to find health information more efficiently with well-designed consumer-friendly terms;
3. May lead to a better understanding of health consumer information seeking behavior in terms of frequently used medical terms and associated terms;
4. May provide health information professionals with useful and first hand information that can be used to update and revise consumer health vocabularies.

Methods

First, we randomly chose fifty de-identified active MyChart® patients and analyzed the terminology differences between diagnosis terms on EpicCare and patient-friendly terms on MyChart® with same patient's health issues. Table 1 shows an example of the terminology differences.

Second, after removing duplicates, we identified 340 unique pairs of diagnosis term / patient-friendly term from the problem lists of fifty selected patients. We then employed UMLS to verify if the term pairs are exact match, synonyms, partial match or not match. We categorized those term pairs that are broader and narrower terms, related and possibly synonymous to be partial match. Of the 340 unique pairs, 18% diagnosis term / patient-friendly term pairs exactly match with each other, 28% are synonyms, 34% match partially, and 20% do not match with each other. Figure 1 shows the matching result of diagnosis term / patient-friendly term pairs.

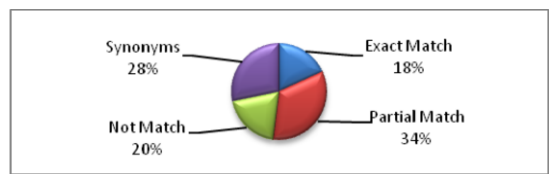

Figure 1 - Diagnosis term / patient-friendly term pairs matching result

Table 1 – Terminology Differences between Diagnosis Terms on EpicCare Problem List and Patient-Friendly Terms on MyChart® Health Issues List

Providers see this screen on EpicCare:	Patients see this screen on MyChart:
Diagnosis	DISORDER OF SWEAT GLAND
Eczema, Dyshidrotic	MENTAL DISORDER
Symptomatic Menopausal or Female Climacteric States	NONALLOPATHIC LESION OF ABDOMEN
Family History of Malignant Neoplasm of Ovary	BREAST ENLARGEMENT
Raynaud's Syndrome	CLOT IN THE LEGS
Globus Sensation	SYPHILIS OF CENTRAL NERVOUS SYSTEM
Somatoform Autonomic Dysfunction	GERD (GASTROESOPHAGEAL REFLUX DISEASE)
Breast Lobule Hyperplasia	HAY FEVER
DVT	PRESSURE-RELATED EAR PAIN
Charcot Joint	MENOPAUSE
Esophageal Reflux	FAMILY HISTORY OF OVARIAN CANCER
Allergic Rhinitis, Cause Unspecified	DECREASED CIRCULATION IN FINGERS OR TOES
Barotrauma, Otitic	

Third, we manually mapped the term pairs that are not exact matches to UMLS to determine their relationship (synonym, near-synonym, closely-related, not-closely-related). For example, we mapped the diagnosis term / patient-friendly term pair "lateral epicondylitis of elbow / tennis elbow" to UMLS and determined they are synonyms in that they are assigned to the same concept unique identifier (CUI) "C0039516".

Forth, after excluding 67 pairs of not-closely-related terms, we mapped the remaining term pairs determined to be synonyms, near-synonyms, or closely-related terms to the keywords of search queries extracted from HealthLink transaction logs to determine the frequency of use by consumers.

HealthLink was an online consumer health resources dedicated to providing consumers with accurate and reliable health information. From 1998-2009, the HealthLink website provided current medical information in straightforward language that explains complex health issues in clear terms. The search terms from the HealthLink transaction log were used to determine the consumer-friendliness for either diagnosis terms or patient-friendly terms in Problem (IT) ™ in this study. These terms from the HealthLink transaction log were not indexing terms employed to index web pages in the HealthLink web portal. Instead, these terms were extracted from the queries submitted from consumers and were used to express a wide variety of customers' health information needs which include those raised from patient records and diagnoses.

Notice that there may be differences between patient-friendly terms in MyChart® and the search terms from the HealthLink transaction log. The primary purpose of patient-friendly terms in MyChart® is to help consumers understand the diagnoses described by these patient-friendly terms. It is natural to use these terms coming directly from consumers to measure the consumer-friendliness of either diagnosis terms or patient-friendly terms in Problem (IT) ™.

We expected that the more frequently the terms have been used for search, the more consumer-friendly the terms are. We chose synonyms, near-synonyms, and closely-related terms for analysis in order to focus on the different ways that health care providers and consumer express the same or similar medical concepts.

To do the mapping, we processed the raw web logs and extracted 3,091,980 search queries from three month's HealthLink transaction logs (October - December, 2008).

Results

Through UMLS, we identified 191 patient-friendly terms as synonyms, near-synonyms, or closely-related terms and their associated diagnosis terms.

Among 93 patient-friendly terms that are synonyms of their associated professional diagnosis terms, 19 of them were used more than 1,000 times in searches within HealthLink queries. 74 of them were searched less than 1,000 times. Table 2 shows the grouped frequency distribution of 93 searched patient-friendly terms that are synonyms of associated diagnosis terms. Among 98 patient-friendly terms that are nearly-synonyms and closely-related terms, 30 of them were used more than 100 times in HealthLink queries and 18 of them were used more than 1,000 times in three months.

Table 2 – Grouped frequency distribution of searched patient-friendly terms that are synonyms of diagnosis terms

Searching frequency	Occurring search terms	Percentage (%)
0-999	74	79.57
1000-1999	8	8.6
2000-2999	3	3.22
3000-3999	1	1.08
4000-4999	3	3.22
5000-5999	0	0
6000-6999	0	0
7000-7999	2	2.15
8000-8999	1	1.08
9000-9999	0	0
10000-11999	0	0
12000-12999	1	1.08
Total	93	100

For each pair of terms, we said that the term used more frequently than the second was more consumer-friendly. In most cases, patient-friendly terms received more searches and were thus more consumer-friendly. However, some diagnosis terms are more consumer-friendly than their associated patient-friendly terms. For example, "lipoma" received 2,166 searches while its associated patient-friendly term "fatty tumor" only got 16 searches. Meanwhile, the diagnosis term "allergy" received 5,601 searches and the assigned patient-friendly term "allergic reaction" only got 1,892 searches.

The most frequently searched patient-friendly term "obesity" was used 12,965 times in search queries over three months, while the associated diagnosis term "obese" was used only 982 times. 86 patiently-friendly terms were not used to search during the three months.

Table 3 shows the most frequently searched patient-friendly terms and their associated synonymous diagnosis terms. Table 4 shows the most frequently searched diagnosis terms and their associated synonymous patient-friendly terms.

These results show that the most frequently searched terms are usually single words or common words. Unlike health care providers who tend to use formal medical terms to describe health concepts, consumers use more simple words or "everyday language" to express those concepts. Sometimes, the professional terms are common enough to express health concepts, which are more frequently searched than so-called patient-friendly terms.

We found that the percentage of both synonyms (28%) and exact match (18%) is less than 50%. The low accuracy rate of the investigated vocabulary system (patient-friendly terms incorporated into Problem (IT) ™) suggests that these patient-friendly terms are not always helpful to narrow the terminology gap between the providers and patients. It shows that a further usability study is necessary and indispensable.

Table 3 - Most frequently searched patient-friendly terms and their associated diagnosis terms

Patient-Friendly Term	Frequency of HealthLink query	Diagnosis Term	Frequency of HealthLink query
obesity	12965	obese	982
diabetes	8447	diabetes mellitus	37
constipation	7445	unspecified constipation	0
high blood pressure	7189	hypertension	2902
urinary tract infection	5534	recurrent uti	23
rash	5005	rash and other nonspecific skin eruption	0
menopause	4984	asymptomatic postmenopausal status (age-related) (natural)	0
depression	4940	depressive disorder, not elsewhere classified	0
stroke	4406	cerebral vascular accident	0
kidney stone	4210	calculus of kidney	0
anemia	4003	unspecified anemia	0
heart disease	3851	unspecified heart disease	0
plantar fasciitis	2995	plantar fascial fibromatosis	0
epilepsy	2568	seizure disorder	97
asthma	2536	unspecified asthma	0
fatigue	2035	malaise and fatigue	0
allergic reaction	1892	allergy	5601
skin cancer	1825	basal cell carcinoma of skin	0
anxiety	1573	anxiety state, unspecified	0
migraine	1503	unspecified migraine without mention of intractable migraine	0

Table 4 - Most frequently searched diagnosis terms and their associated patient-friendly terms

Diagnosis Term	Frequency of HealthLink query	Patient-Friendly Term	Frequency of HealthLink query
gallstone	7766	gall stone	676
allergy	5601	allergic reaction	1892
lipoma	2166	fatty tumor	16
hypothyroid	1556	underactive thyroid	83
osteopenia	1393	bone disorder	0
neuropathy	1150	disorder of a single nerve	0
bph	700	enlarged prostate	0
edema	578	generalized swelling	0
lymphoma	535	malignant lymphoma	0
esophageal reflux	509	gastroesophageal reflux disease	346
hernia	452	abdominal hernia	0
coronary artery disease	403	heart disease due to blocked artery	0
eczema	342	allergic dermatitis	0
osteomalacia, unspecified	322	bone softening	0
varicose vein	197	varicose veins of legs	0
vocal cord paralysis	192	paralysis of vocal cords	3
ovarian cyst	174	cyst of ovary	0
attention deficit hyperactivity disorder	166	attention deficit disorder with hyperactivity	0
periodic limb movement disorder	153	periodic limb movement sleep disorder	0
sacroiliitis	90	sacroiliac inflammation	0

The findings of this study are based on 340 terms from the fifty de-identified patients' records from MyChart®. When the patient sample size increases, the number of the extracted terms will increase accordingly. As a result, the findings might be different. Notice that structure and coverage of a patient database also play a role in the final findings. If the same research method were applied to a different patient database, the results might be also different.

Conclusions

Health care professionals and consumers use different vocabularies to express health concepts. The use of patient-friendly terms could help to bridge the language gap but not always. If the professional terms are more simple or common than the assigned patient-friendly terms, they are more consumer-friendly. In this case, we should choose the same terms that professionals use instead of displaying the terms that are not really patient-friendly in order to avoid increased misunderstandings.

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