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Consumer Health Vocabulary

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Patrick et al. [1] have called the "consumer vocabulary problem" a fundamental issue in health information provision. This is the problem of mismatch between terms used by healthcare professionals and those used by the consumers who receive their services. Compatibility, between consumer and clinical terminology, or the lack of it, has been investigated in domains including Web site usability [2–4], information prescriptions [5], and HMO report cards [6]. The issue is seen as so important that one packaged consumer vocabulary was advertised as the "Rosetta Stone for the consumerization of healthcare" [7].

In fact, the consumer vocabulary problem is a very old one. Mazur [8] notes that "basic communication . . . has perplexed medical science, doctors and patients since at least the late 1700s" and Andrews spoke of the old dichotomy between scientific and "lay" terminology in his classic *History of Scientific English*:

> The background of medical English . . . is utterly at variance with the usual ancestry of a language . . . Ordinary speech is controlled from below; the masses make and remake it in defiance of scholars who reluctantly have to accept the speech of the populace as their own. With the scientist, however, the written word rules the spoken word, and regular regeneration of older changing words is a steady process. [9]

The first consumer health vocabulary may in fact have been English. Words that had "escaped" from scientific books with the advent of the printing press soon became part of popular speech; so, for example, in the fifth act of Shakespeare's *Henry IV*, Part II, the clown Mistress Quickly addresses the First Beadle: "Thou atomy, thou!" using lay slang for *anatomy* or *cadaver*, while her colleague Doll Tearsheet cries synonymously "Goodman bones" [10]! Greenberg [11] looked at the effect of Gutenberg's printing press on public health information dissemination in 17th-century London: health information for the first time *expressly intended for the public*, printed in English and not solely for the Latin-speaking physicians of the day.

Historically, the terminology for consumer terminology in health has been *lay language*. Mazur ascribes the origins of this term to the judicial system and defines it as "scientific description for nonscientists . . . the nontechnical language of consumers, patients and others" [12].

Language, meaning, relationships between terms, and disease models all contribute to the comprehensibility of health information being transmitted. We understand new information by applying the new knowledge to preexisting cognitive models. If the disease model is not congruent with the prevailing one, it may not be understood. One complication, however, is that the perspective of the objective scientific researcher may

inadvertently bias his or her understanding of the patient's model. Tedlock [13] investigated the presence of the "hot–cold" categorization of Galenic humoral medicine in Latin American traditional healing practice, a model being blamed for purported interference with orthodox Western healthcare. He found that contrary to anecdote, highland Guatemalan traditional healers "did not include hot–cold categories in their explanatory models of illness etiology," but that anthropologists who asked questions of *patients* that incorporated these dichotomous categories were likely to receive appropriately hot and cold answers. Ironically, for the purposes of this chapter, the confusion of practitioner language with lay language was part of the research problem.

With that caveat in mind: Is there such a thing as a consumer health vocabulary? Are there in fact unique concepts that are not already represented by professional, clinical vocabularies? These questions are addressed in the following section, through discussion and review of relevant research.

Research Themes

We can structure our discussion of vocabulary issues in consumer health in three main areas:

1. Patient–physician communication: information flow from physician to patient, for example, in the context of obtaining informed consent
2. Patient interpretation of print and media: the information itself observed in transit
3. Consumer health vocabulary: information flow from consumer to information retrieval system and back again, for example, in the context of information seeking online

Central to each of these themes is patient interpretation—with affective overtones—of medical concepts.

We understand concepts or retain vocabulary differently based on our state of mind. If we are under stress, we might need someone with us when we talk to the doctor, and a written summary of what we are being told so that we can refer to it later. Even when we are not under stress, we may not understand the now increasingly more readily accessible medical information we come across when attempting to self-diagnose. Do current vocabularies, such as those represented in the Unified Medical Language System (UMLS), already incorporate concepts that a consumer might use? The affirmative posits that although there might be some "consumer terms" unavailable through the UMLS, as the concepts are already represented, it is simply a question of adding synonyms. The opposing argument suggests that it is likely additional concepts need to be constructed, arising from the different cultural models of health, disease, treatment, and mortality found in the United States population.

What is under discussion in this chapter is consumer vocabulary in service of communication, understanding, and information seeking. This chapter does not provide an exhaustive review of these topics, but rather approaches a synthesis of the critical issues that must be addressed.

Patient–Physician Communication

Patient participation in the decision making process is vital in today's healthcare system. The key to participatory health care is communication, and the key to communication is informed participation in the dialogue. Informed participation is bidi-

rectional: the patient must understand what the physician and the literature say, and the physician must understand what the patient says.

Mazur [12] proposes that patient–physician communication must begin with "the patient's understanding of the information disclosed, *in lay language*" (italics added). This is an ancient concern: language that was intended for physicians was considered actively harmful when applied to nonphysicians. Connor in 1963 voiced the typical attitude of medical librarians when he wrote: "The average patient normally does himself more harm than good when he tries to determine even in a scientifically sound tome his own diagnosis and therapy. The avenues of approach are so many and the language so highly technical that even the intensely trained physician frequently must work hard to comprehend and make the appropriate choice among many alternatives" [14] and even today, Williams et al. [5] cite "terminology" as one reason for providing librarian-mediated translations in Vanderbilt's PICS (Patient Informatics Consult Service). However, this is not simply a matter of vocabulary; in other words, use of a common language at a level of comprehension appropriate to the person may not be enough. The education of patients may not be successful if, for example, written material is not comprehensible to the patients' own belief system: If a patient and her physician have different conceptual models of illness and health, then any ensuing dialogue will only be as effective as the fit between the patient's cultural model and the physician's. Language barriers were one of the four factors cited by Buchanan et al. as "stand[ing] in the way of effective doctor–patient communication" [15]. Not only have the linguistic forms of medical language been implicated in the creation of distance during treatment [16] but the very name of the illness has historically been known to have an effect on the patient [17,18]. Chapple et al. [19] addressed the emotional ramifications of clinical terminology in the "anxiety and confusion" among families in genetic counseling situations. Their work goes beyond identification and definitional experiments, taking into account the anxiety accompanying the patient's search for understanding of a disease or condition; and how the words chosen in trying to present information can go a long way to diminish that anxiety. In an online environment, we might consider replacing the term *abnormality* (worst possible scenario unfolding) with the term *chromosome variation* (understood as "something different"). Do we know whether this replacement will not only diminish anxiety, but also enhance understanding? We have nonverbal cues to go by in a face-to-face encounter, to which we can quickly adjust; but we do not have that advantage with printed text shared at a distance, nor do we know how consumers really interpret the content of Web sites such as *ClinicalTrials.gov.*

Communication and Vocabulary

Even if clinical terminology does exist to represent a particular consumer-oriented concept, its placement or context in a controlled vocabulary determines, to a certain extent, its meaning. *Tobacco* illustrates how contextual placement in a thesaurus represents the conventional meaning of the term. Hypothetically, both an allopathic view of medicine and a more traditional (for example, Native American) perspective would place *tobacco* in an agricultural, or crop, context. The allopathic view would also place it in a context representing an ingredient in cigarettes, a recreational or carcinogenic substance, something marketed and sold to people who may become addicted to the carcinogenic substances that are byproducts of the smoke. In traditional Native

American culture, however, tobacco has religious significance used ceremoniously; its primary function is not as a recreational substance.

The use of clinical terminology itself can be a signal of context: AHCRQ (the Agency for Healthcare Research and Quality) and the Kanter Foundation, in their publication "Now You Have a Diagnosis: What's Next?" note that patients must beware of documents relying on "the use of medical-ese – impressive technical terms to help make treatment decisions" [20]. Contrast this, however, with the interesting finding of Ogden et al. [21], who presented 740 patients in 3 English counties with 2 prepared scenarios of clinical diagnoses, randomly expressed in lay terminology, medical terminology, or a combination of the two (for example, *stomach upset* as opposed to *gastroenteritis*). These authors found considerable differences between lay and medical labels for the same diagnoses; patients consistently rated the medical labels as beneficial for the validation of their "sick role" and improving their confidence in their doctor. Lay labels, on the other hand, were associated with assumption of responsibility and taking of blame.

Patient Interpretation of Print and Media

In a landmark study published in 1970, Boyle [22] published a study that is relevant today to the way in which patients may interpret the written word. Two hundred and thirty-four outpatients and 35 doctors completed multiple-choice questionnaires aimed at evaluating differences in interpretation of commonly used medical terms. Part of the instrument asked patients and doctors to select which of four figures portrayed the correct anatomical placement of certain organs. One finding of the study was that patients had trouble locating various body parts, suggesting, for example, that in the absence of active communication, a patient might misconstrue the site of an unexplained pain. To add to the confusion about terminology presented in print, not all physicians in this study were able to correctly identify the heart! Similarly, not all physicians agreed on the definitions for either *constipation* or *diarrhea*. In fact, doctors and patients disagreed on most definitions except what is meant by *a good appetite*. Hadlow and Pitts [23], working in England, found similar results from 120 patients and 100 doctors and support staff asked to define common medical and psychological terms; these authors found significant differences in levels of understanding strongly associated with the level of medical education.

A person in a state of grieving brings an emotional overlay to any information-seeking task. The affective component of the terminology needs to be sensitive to such potentially emotional states. "Misconceptions cannot be easily addressed using a static, printed handout" [24].

Consumer Health Vocabulary and Information Seeking

Sievert et al. [25] start to address consumer health information seeking from the information retrieval perspective. They have brought the common term *conundrum* to the query formulation stage and demonstrate that search results can be confounded by the way most search engines deal with lexical variants, particularly as they have become more sophisticated and often err on the side of recall over precision.

Finding Out What Consumers Say

One guiding assumption in this research domain is that consumers have their own "language" susceptible to analysis. Any study of consumer "language" will beg the question of what terms consumers actually use.

Therefore, two significant challenges to consumer terminologists are the definition and the capture of terms that accurately reflect consumer reality. One straightforward strategy used by a number of researchers in different disciplines has been to ask the consumers themselves. Both Barrett and Wellings and Fischer et al., for example, surveyed the relationship between intentional achieving of pregnancy and the terms the pregnant women used to describe those pregnancies, finding them "highly correlated to social and cultural influences" [25,26]. Two British studies have used this same approach and discovered that consumers don't particularly want to be called consumers. In England, Batra and Lilford [27] asked 100 pregnant women what they would like to be called and found *mother-to-be* and *pregnant woman* more popular than *client*, *consumer*, or *maternant*. Four years later in Wales, Byrne et al. [28] also found *patient* the most popular term for "women attending antenatal clinics," with *consumer* being the least favored of all.

Similarly, several studies have investigated the cultural dimensions of consumer language. Schorling and Saunders [29] asked 1031 rural African Americans if they had "sugar" or "diabetes." Of those who responded affirmatively to "sugar," 31% answered "No" when asked subsequently if they had diabetes. Interestingly, those subjects who used the term *sugar* also believed their condition to be less serious. Blumhagen [30] posited the existence of a physical illness called "hyper-tension," "characterized by excessive nervousness caused by untoward social stress" and used by some people in his study to explain and justify particular social behaviors. Thirteen years later, Heurtin-Roberts [31] delineated a chronic folk illness among elderly African-American women in New Orleans that they called "high-pertension" and believed to involve "blood and nerves."

Another strategy to enhance usability of information targeted at consumers is to involve patients themselves in the development of their own educational material, for example, clinical practice guideline composition [32]. Content analysis of query log files and e-mail messages can also provide a new perspective on consumer vocabulary. For example, McCray et al. [3] examined 3 months' worth of queries submitted to the National Library of Medicine's home page. These authors were able to identify common terminological problems in query formulation, ranging from translation errors ("psicology") to transcribed verbal slips ("prostrate cancer"). Patrick. Sievert et al. [1] looked at e-mail messages and extracted words and phrases from print publications explicitly authored by consumers, raiding the *Dictionary of American Regional English* for their folk equivalents. Smith et al. [33] examined e-mail messages submitted to a Web-based cancer information service marketed to the general public at the University of Pittsburgh Medical Center. Messages in which writers self-identified as healthcare providers (doctors, nurses, medical students) were eliminated from analysis. In this study of 139 e-mail messages, the terms these e-mail writers used to express their health information needs overlapped in 96% of the cases with terms from the 92 healthcare terminologies comprising the 2001 UMLS.

Is the Consumer Different?

Many researchers contend, conversely, that there is no "consumer vocabulary." The results of Smith et al. [33] showed almost universal consonance between lay terminology and that of healthcare professionals. In fact, two unique e-mail writers used the same word to describe their cancer diagnosis—*cribriform type*—a phrase not found in any UMLS source vocabulary, but a perfectly correct clinical term meaning *sieve-like* (for the appearance of the cancer cell). Far from demonstrating a preference for slang, in this case two consumers excelled the UMLS in granularity of expression.

Zeng et al. [34], however, found poor matches between the UMLS and terms that patients used to search a hospital Web site. These authors' recommendations included the development of vocabulary tools to assist in the search process. Patrick et al. [1] studied controlled vocabulary resources to evaluate their potential to accommodate the consumer terminology used to describe *diabetes*. This study emphasized differences between consumer and physician terminology and how the latter helps to focus retrieval on the World Wide Web. This work also suggested that the addition of "vernacular terms" would enhance searching on the Internet.

Conclusion

"Lay conceptions of disease," as Chapple et al. call them [19], may be based on many factors beyond sound—or shared—medical facts. Shared decision making is subverted when doctors and patients understand the meaning of certain terms in different ways. Computer-based programs designed to facilitate decision making need to take this divergence into account. However, to facilitate the process of context provision, the transmitter of the information must understand the model that will be infiltrated; then the words used will be related to each other in strings and sentences in a meaningful way. The problem of understanding a concept but not remembering the correct word for it is one that can be addressed during the communication process. If the consumer can communicate a given concept to a healthcare provider, then translation into clinical terminology is still possible.

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