Graphical Mapping Of A Data Ontology For Capturing Descriptive Patient Data

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ABSTRACT

Capturing a patient's personal health data in medical forms is challenging. The symptoms of an illness can often be located to an activity or a body part, and communicating this to an untrained patient is often unclear. To address this problem, we mapped an ontology of human disease phenotypes to a graphical depiction of the human body. We hypothesized that describing the experience of illness in a somatic representation would give patients a more accurate and descriptive understanding of their illness. The representation can support health care workers to provide more accurate analyses, aid caretakers in managing health risks and empower patients to take action to better their health.

KEYWORDS

Human-centered computing ~ Activity centered design; Human-centered computing ~ Accessibility design and evaluation methods

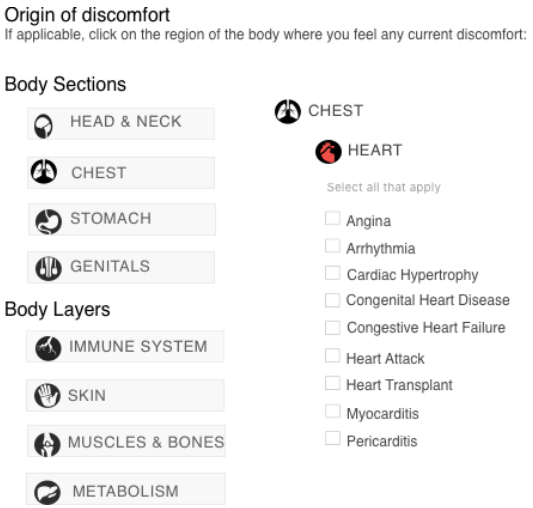

Figure 1. Segmentation of the HPO into Sections and Layers

INTRODUCTION

Electronic Health Records (EHRs) are designed to provide instant access across networks of caretakers and secure data housing for better care, yet they carry on the western tradition of the depersonalization of health care. While serving as a valuable knowledge source for health care workers, the EHR replaces dialogue with the patient by a one-sided extraction of information. This raises the need for tools that can provide a two-sided dialogue in which the interface provides the patient information as well as medical understanding.

Adding to the communication challenges of EHRs is the increasing complexity of medical tests and their interpretation. Declining costs of biomolecular testing and Big Data advances in analysis methods have made commercial precision medicine tests more accessible, increasing the need to interact with EHRs. These more complex reports create additional challenges for health analysts in understanding the patient experience in order to better communicate results in ways that are compatible with the mental models of patients, caregivers and analysts.

PATIENTS, CAREGIVERS AND ANALYSTS

The capacity to understand and represent the body and its conditions is variable across patient care spectrum. Conventional medical forms for biomolecular analysis are designed for physicians knowledgeable in the format and content. The high barrier for understanding complex ontologies and terminology used by physicians can impede communication with patients and caregivers[3]. Confronted with a poorly understood representation, patients may attempt to research their conditions independently which can add to an already confused state. An emerging stakeholder in healthcare, the health data analyst, requires extensive and precise patient-generated symptomatic information in order to accurately report health test results. The communication loop between patient and caregiver is expanded by including health data analysts.

THE HUMAN PHENOTYPE ONTOLOGY (HPO)

The HPO is a tool that provides a set of disease risks and phenotypes, and categories that show their properties and the relations between them [1]. Among those properties is the inclusion of “layperson” descriptions of conditions, (e.g. Palmar pruritus vs Itchy palm) [2]. Still, these lay synonyms are abstract concepts in relation to the patient’s embodied experience.

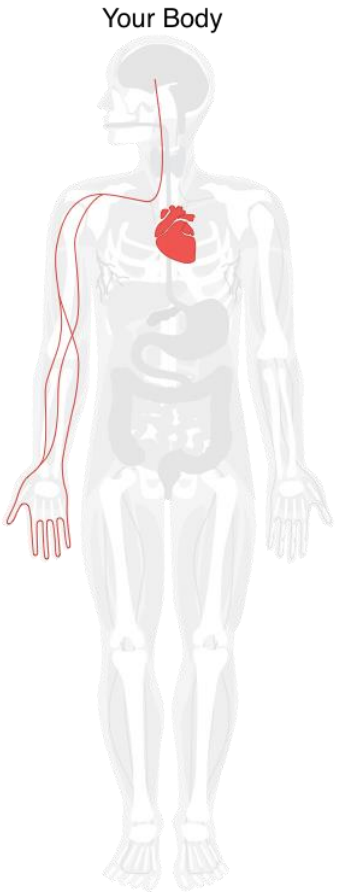

Figure 2. Graphical depiction for feedback after clicking

MAPPING HPO TO A BODY GRAPHIC

Mapping of the HPO's hierarchical structure traces the semantic relations of phenotypes across body systems and organs and visualizes the symptoms in a body graphic. As seen in Figures 1 and 2, this graphical re-interpretation of the ontology can better match the patient's mental models of their body and experience. Through interaction with this representation patients can navigate through functional systems such as the immune system, and body sections. This reduces the need to comprehend medical terminology.

The lay synonyms of the HPO can replace medical terms for easier disease recognition during exploration. Future work could focus on the educational aspects of making patients better understand their disease embodied experiences. Finally, the data infrastructure is expandable, supporting the design of visualizations that match innovations in analytic methods.

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