Development of a Virtual Self-Management Tool for COPD Patients: Towards a User Needs Ontology

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Abstract
Chronic Obstructive Pulmonary Disease (COPD) is a significant cause of disability. The purpose of this paper is to present our work in the development of an ontologically based patient COPD self-management web technology. In Phase I we conducted an ethnographic study to learn about the information needs of COPD patients. In Phase II an ontology of patient information needs was developed to guide the organization and development of a Web-based self-management management tool. Phase III of this work involves completing the development of the Web-based tool using the ontology developed in Phase II.

Introduction
Chronic Obstructive Pulmonary Disease (COPD) is a significant cause of disability. In recent years there has been a shift towards the use of technology in the delivery of health care. According to this research, there is considerable value associated with the use of web-based technology in the self-management of COPD. Research suggests web-based self-management tools can help patients reduce the symptoms of disease and health care service utilization. This has led some researchers to conclude web-based means of helping patients self-manage their disease are a cost-effective method of improving the quality of patient self-care. The purpose of this paper is to present preliminary results from Phase I and II of our work in the development of an ontologically based, patient specific, web-based, self-management tool.

Method
In Phase I an ethnographic study was undertaken to learn about COPD patient information needs (i.e. concerns) and self-management (i.e. coping) strategies (n=20) in moderate to severe COPD patients. Subjects were interviewed using a semi-structured questionnaire. Data were collected from audio taped interviews with each participant and analyzed using an ethnographic approach to identify recurrent themes. Based on the results of Phase I an ontology of patient information needs was developed and compared to health professional models of disease management. The ontology proved different from traditional models of health professional based orientations towards teaching patients about the self-management of their disease. The ontology is currently being used to guide the organization and development of a web-based virtual self-management tool for Phase III.

Results
Initial results suggest that a link exists between patient information needs and self-management strategies. Ethnographic analysis revealed patients had primary and secondary information needs. Dyspnea was a primary information need. In contrast, all secondary information needs arose from the primary information need (i.e. dyspnea). Findings suggest patient cognitive linkages between concepts, as illustrated in the ontology, differ from those of health professional educators for this group as published in the literature.

Conclusions
Our research has demonstrated health professionals and patients differ in terms of their cognitive mapping and linkages between COPD information needs and self-management strategies. There is a need explore the impact of designing tools based on patient cognitive structures and understandings of disease in order to determine if cognitive maps of patients lead to better patient outcomes and reductions in health care service utilization as compared to more traditional health professional based educational and self-management programs.

References