Influence of Lay Conceptions of Health and Illness on Health Care Decision-Making: Implications for the Development of Technological Support

Cytryn, Kayla N., M.Sc.¹, Patel, Vimla L., Ph.D., D.Sc.¹, and Cimino, James J., M.D.² ¹Cognitive Studies in Medicine: Centre for Medical Education, McGill University, Montreal, Quebec ²Department of Medical Informatics, Columbia University, New York, NY

Objective: Treatment of Acute Myocardial Infarction (AMI) has advanced for patients who receive it quickly, yet not all do¹. Computer technology can provide educational programs reducing delays in receiving treatment if based on an understanding of lay people's reasoning about health, illness, AMI, and technology. In order to design educational programs that will achieve desired changes in lay behavior, a better understanding of lay knowledge and reasoning is needed². We therefore examined lay conceptualizations of health and illness, how these conceptualizations are translated into action, and knowledge sources about health and illness.

Methods: *Subjects:* Three groups of subjects were drawn from: 1) patients at risk for AMI, 2) patients with illnesses other than cardiac, and 3) lay people identified as healthy. *Procedure:* Semi-structured interviews were conducted focusing on lay reasoning about health and illness, particularly AMI. Scenarios were developed describing varying levels of gravity requiring different levels of urgency of action, and subjects were instructed to think aloud as they reasoned through the problems. All interviews were audio recorded for subsequent analysis. *Analysis:* Specific concepts were identified in the verbally generated protocols based on coding categories developed from the literature and our own research³.

Findings: (1) *Health* is predominantly described as feeling well and able to carry out daily activities independently while *illness* is perceived as a reduction in that ability. Healthy subjects put more emphasis on absence of illness and symptoms in their descriptions of what it means to be healthy compared with subjects with illness. (2) The major source of health-related information reported by subjects was their physician, with friends, family, the media, and the Internet being represented as well. Healthy subjects relied less on physicians and more on informal sources, including technology. (3) Knowledge about disease: All three groups of subjects identified some symptoms of AMI, i.e. chest pain and dyspnea, but were less able to identify other symptoms. None could identify all or even most symptoms. (4) When confronted with these symptoms in scenarios, the most frequent response by each group of subjects was to access emergency services, which was appropriate to the gravity of the

situation. Both groups of subjects with illness also responded by contacting family members or friends. **Conclusions:** Differences between the health and illness models of healthy subjects compared with those who have had experience with illness suggests that experience molds those models, with the understanding of wellness in particular developing through experience with illness. The sources informing these models are those that are part of day-to-day life, generating incomplete knowledge based on selective attention and the impact of images. Even when symptoms of AMI are known, decisions about actions are strongly influenced by variables such as anxiety and uncertainty.

Implications: That ineffective responses reported by subjects to familiar symptoms of AMI is of concern because these behaviors have been shown to increase delay in patients' receiving appropriate care for AMI⁴. Technology provides an education method that is part of people's everyday lives and supports the acquisition of personally tailored information as they browse in familiar, accessible settings⁵. We therefore recommend that education emphasize maintaining and returning to normal functioning, providing information and clear, simple, personalized instructions as to how to respond to symptoms, including simulations, scenarios, and role playing.

References

- 1. Gunby P. Cardiovascular diseases remain nation's leading cause of death. JAMA 267:335,1992
- 2. Sivaramakrishnan M & Patel VL. Reasoning about childhood nutritional deficiencies by mothers in rural India: A cognitive analysis. Soc Sci Med 1993;37:937-952.
- 3. Cytryn KN & Patel VL. Reasoning about diabetes and its relationship to the use of telecommunication technology by patients and physicians. Int J Med Informatics 1998;51:137-151.
- Weaver WD. Time to thrombolytic treatment: Factors affecting delay and their influence on outcome. J Am Coll Cardiol 1995;25(supp.):3S-9S.
- 5. Cimino, J.J., Sengupta, S., Clayton, P.D., Patel, V.L., Kushniruk, A.W., Huang, X. Architecture for a Web-based clinical information system that keeps the design open and the access closed. In C. Chute (Ed.) Proceedings of the AMIA 98 Annual Symposium 1998;121-125.