

Chapter 3.28

Identifying Optimal Chronic Kidney Disease Patient Education Web Sites: Assessing E-Health Technology by Content Area Experts

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ABSTRACT

One in nine adults in the United States has chronic kidney disease (CKD). Randomized studies show electronic health (e-health) systems improve health outcomes in chronic disease. This study describes a systematic evaluation of available CKD Web sites. We evaluated Web sites for educating patients with CKD, focusing on three specific design issues: usability, quality, and content. Thirty Web sites were evaluated between April and July 2004. Cohen's kappa and intraclass correlation of quartile rankings for two independent evaluators were calculated. Mean score for evaluator 1 was 7.293 (standard error 0.511) and for evaluator 2 was 8.189 (0.413). Cohen's kappa for the 2 evalua-

tors' total scores for all 30 Web sites is 0.7671, and intraclass correlation is 0.7703. In general, results show that it is possible to identify Web sites more likely to provide a positive educational experience for CKD patients. Further evaluation is needed to investigate the utility of variably ranked Web sites as educational interventions.

INTRODUCTION

Medical informatics has traditionally consisted of applications to improve information exchange, decision-making, and time management for health care professionals. As the fundamental relationship between patients and physicians has changed

from paternalistic to partnership, the informatics focus is shifting towards the consumer (Eysenbach, 2000). The objectives of this transition are to empower patients with appropriate medical knowledge, education, and the tools for self-management. This may be particularly effective in enhancing patient and health care provider partnerships in the management of chronic disease (Celler, & Lovell, 2003). According to the Pew Research Center, a nonpartisan organization that provides information on national and global trends, 70% of the health care consumers, who are influenced by online information, report that the Internet affected their decision making about health care (Fox, & Rainie, 2002). Still, very little is known about how patients judge health information obtained on the Internet. Moreover, data suggest that while health care consumers are facile at obtaining answers to directed health questions, they seldom assess the quality or source of the information. Consumers also tend not to remember Web sites from where they acquired the information (Eysenbach & Kohler, 2002). Thus, health care provider-sanctioned Web instruction is needed to help alert and direct patients to information that is valid and accurate.

One in nine adults in the United States has chronic kidney disease (CKD) (Coresh, Astor, & et al. 2003). This creates a tremendous public health burden, with more than \$22 billion in spending on the end-stage renal disease (ESRD) program in 2002 (USRDS, 2002). Slowing the rate of loss of kidney function in later stages of CKD by 10-30% could save \$5 to \$30 billion dollars in health care expenditures over the next decade (Trivedi, & Pang, 2002). Prior to end-stage disease, there may be opportunities to slow progression and delay disease complications, but patient education is vital. Time constraints prevent clinicians from taking on the task of repetitive patient education and counselling. However, customized Web sites available via the Internet may be able to fill this need by providing novel ways to reach patients with CKD.

Randomized studies have found that e-health systems can improve knowledge, self-care, quality of life, coping skills, health care participation, and health outcomes in chronic disease, as well as self-management behaviors, including diet, exercise, medication taking, and health utilization (Gustafson, & Hawkins, 1999a; Gustafson, & McTavish, 1999b). However, very little is known about the selection of e-health Web sites and the assessment of medical information obtained by patients (Eysenbach & Kohler, 2002). There are a number of CKD patient education sites available on the World Wide Web, some of which are sponsored by not-for-profit organizations and some by private industry. Few are written at a level so as to be useful to the general population, and many do not comply with available standards for health Web sites (Calderon, & Zadshir, 2004a; Calderon, & Zadshir, 2004b; Jaffery, & Becker, 2004).

Additionally, as research in the field of e-health expands, it is becoming increasingly clear that in order to capitalize on the potential power of the Internet as an educational tool, innovative methods for communicating with patients is needed. Marill, Miller, and Kitendaugh (2006) report on the ongoing challenges to the National Library of Medicine's Medline Plus, highlighting the dynamic process inherent in health information Web site design.

Although more literature is emerging on optimizing human-computer interactions for specialty clinical areas and the education of chronic disease patients, to date, much of this has been led by the cancer and mental health arenas (Bader, & Strickman-Stein, 2003; Chelf, & Deshler, 2002; Chernecky, & Macklin, 2006; Chou, & Lin, 2004), with limited contribution in the nephrology literature. The purpose of this manuscript is to describe a systematic evaluation of readily available CKD Web sites. A more comprehensive review of these sites revealed significant deficits that are likely to impair their usefulness as educational tools.

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