Lost, Found, and Feeling Better: Exploring Proxy Health Information Behavior
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In studying how people use the Internet for situations involving consumer health information (CHI), we also examined the phenomenon of proxy searching, i.e., when people seek information on behalf of others without necessarily being asked to do so or engaging in follow-up. Proxy searching has also been referred to as the imposed query, or a query which is precipitated by questions generated by others, such as teachers, employers, friends, or family members (Gross & Saxton, 2001). The prevalence of proxy health information seeking has been observed to be as high as 54% of all health information seekers on the Internet (Fox & Rainie, 2000). Many health care researchers refer to these information seekers as "hidden patients" and have noted the importance of addressing their information needs, particularly because these needs can become lost among those of the patients they are related to (Meissner, *et al.*, 1990; Ell, 1996; Kristjanson & Aoun, 2005). The needs of these hidden patients are often negotiated by others who are largely not information professionals, so their behaviors regarding how they further seek, use and don't use information in formal situations are also invisible. To date, little information science research has focused upon proxy information behavior specific to the health care context.

As part of our study on Internet consumer health information behavior, we investigated people's motivations for, uses, and the effects of proxy health information behavior through online surveys (n = 207) and follow up telephone interviews (n = 21) with visitors to http://www.nchealthinfo.org -- an NLM-sponsored and University of North Carolina at Chapel Hill-run, health resource that provides statewide health provider listings and MEDLINEplus database access. We used three different surveys and interview guides, one for each of our participant types: direct users (those searching on behalf of themselves), service providers (those searching in a professional capacity), and proxy searchers. Participants self-identified themselves as one of the three types. The proxy and the direct user survey and interview guides specifically focused on proxy searching behavior. All surveys and interviews included questions on topics such as health information needs, information seeking behavior, barriers faced in obtaining and/or providing information, anticipated information uses and outcomes, actual information uses and outcomes, and the nature of proxy or provider contacts and relationships. Survey questions addressing barriers faced by health information seekers were based on the work of Baker and Manbeck (2002).

We compared and contrasted our results with those reported by information science researchers who have studied proxy searching in other settings (e.g., Erdelez, 1996, 1999; Gross, 1995; Gross & Saxton, 2001; Erdelez & Rioux, 2000; Pettigrew, *et al.*, 2002; Rioux, 2004) and examined them with respect to several information behavior theories regarding human communication and social relations. Our results indicate that proxy health information behavior shares many of the same attributes discovered in previous studies, but may also exhibit characteristics that are unique to the health care environment. We

suggest that these findings may have implications for CHI system and health services design and could inspire further research in information science, biomedical informatics, and health care quality and outcomes.