Collaborative Information Behavior in Families Dealing with Chronic Illness

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Project Description:

Rationale. Chronic diseases - the leading cause of death in the United States - are prolonged illnesses which can be controlled but not cured. This study projects focus on families confronting HIV/AIDS and diabetes, two serious illnesses which can be managed long-term with demanding treatment and self-care regimens. The onset of chronic illnesses such as these is a significant, negative life event that present challenges across numerous areas of a person’s life. Moreover, chronic illness not only affects the ill person, but also has important consequences for his or her loved ones.

Health information is an important resource for both people with HIV/AIDS and diabetes. While this prior research has taught us a great deal about the importance of information to ill individuals, it rarely addresses the collaborative nature of responding to illness. As such, we know very little about collaborative information behavior in this context. And while the growing field of collaborative information behavior research could potentially offer insight into health information behavior within families, this research primarily focuses on work contexts. However, as my prior research about HIV/AIDS information exchange showed, people with HIV/AIDS and their friends and family members obtained information in ways that were more voluntary, loosely coordinated and emotionally rich than were described in previous employment-related research. Additionally, my prior collaborative research showed that families managing chronic illness used time-based information objects such a calendars and medication containers in ways that managed emotional intimacy between family members.

As such, it appears that collaborative information behavior may have unique characteristics in everyday life. Further research is needed in order to deepen our comprehension of these unique characteristics. In particular, gaps remain in understanding information behavior in the family as a whole. This is important because families are more than a collection of individuals – indeed, there are dynamics that can be understood only when looking at the entire group. In recognition of this, this project investigates family-level health information behavior by examining information activities at both individual and group levels. This research will therefore offer insight into information behavior which cannot be gained when studying individuals alone.

Academic Objectives. This project focuses on answering the questions, “What chronic illness-related information activities do family network members engage in, as individuals or groups?” and ”How are information activities negotiated, coordinated or jointly performed between different family members?” To answer these questions, this project will draw from data collected as part of a two-year study of 39 families (including 97 individuals) who are dealing with HIV/AIDS or diabetes. The data set includes five interviews per family, surveys, and photographs from “home tours” in which participants showed the research team how they manage illness at home.

Since data are already collected, this project will focus specifically on data analysis and interpretation, synthesis of existing literature, and scholarly writing. A goal of the paper will be to contribute to theoretical insights regarding collaborative information behavior; accordingly,
there will be an emphasis on qualitative analysis of interview transcripts and photographs according to existing information behavior theories, and on conducting analyses that facilitate the generation of new concepts and theories. Additionally, there will be opportunities to test theoretical relationships through analyses of survey data. These theoretical contributions will provide a basis for the future design of information technologies and services to better support the illness-related collaborative activities of families.

**Student Participation:**
The student trainee will serve as a research assistant for the project. In this role, I will mentor him/her in the entire process of scholarly writing, from literature review to data analysis to writing and revision. Accordingly, he or she will: 1) synthesize literature in an area of research; 2) categorize and code interview and photographic data using a mixture of analytical approaches; 3) conduct statistical analyses of survey data; 4) prepare a manuscript that addresses the research questions; and 5) gain experience with the processes of paper submission, revision, and publication.

**Contribution to Student Academic and Professional Development.** The student will gain experience with organizing, analyzing, and presenting multiple types of data. He or she will gain skill in discerning the quantity and type of qualitative data that is required to produce a publishable journal article in the field of health information science. He or she will have the opportunity to learn how to position research questions in the context of published literature, how to describe and report research methods, how to report results, and how to reflect upon the implications of reported research. He or she will also learn how to prepare and submit manuscripts, and how to manage manuscript revision processes as required.

**Mentoring Plan:**
I will meet with the student on a weekly basis throughout the project. Additionally, we will work together more closely as we begin each new phase of the study. I will provide instruction in data analysis methods, and I will provide feedback on coding, memos and other results of analysis. I will also instruct the student in writing for a scholarly audience, and provide detailed feedback on manuscript drafts first prepared by the student.
References