

Methodology for the Evaluation of Health Information by Participants with Low Literacy Skills

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Abstract

This poster presents a case study method developed for a pilot study investigating the evaluation of print- and text-based consumer health information by individuals who have low or limited literacy skills in English. The methodology is based on the theory of Everyday Life Information Seeking, usability research, community-based participatory research, and research with vulnerable populations.

Keywords: Methodology; user-centered research; literacy; consumer health information; health information behavior

doi: 10.9776/16492

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Acknowledgements: This research was conducted in collaboration with Diaspora Community Services.

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1 Introduction

LIS needs a guiding framework for conducting user-centered research specifically designed for working with vulnerable or marginalized communities. This requires special considerations such as determining the appropriate manner of data collection, identifying the implications of different data collection methods vis-à-vis power dynamics inherent in the research process, ensuring data integrity, and preserving the participant's sense of agency throughout the study. Following is a set of data collection methods based on strong methodological considerations and developed for a qualitative pilot study designed to investigate how individuals with low literacy skills evaluate consumer health information about diabetes.

2 Problem Statement

Consumer health information can be extremely difficult for people to understand regardless of their level of education or literacy skills (Jacobson, 2013; U.S. Department of Health and Human Services, 2008). The work presented here contributes an intentional methodology based on an ecological approach to community-based participatory research (Israel, Schulz, Parker, & Becker, 1998) and the theory of Everyday Life Information Seeking (Savolainen, 1995), and applies it to a user-centered pilot study that examines consumer health information behavior among adults with low literacy skills.

Several studies model how people evaluate different types of information found online, including health information (Eysenbach and Kohler, 2002; Fox and Rainie, 2002; Hilligoss and Rieh, 2008; Yi et al., 2012). Because most of these use convenience samples and mostly focus on information resources available online, they do not explain, for example, how individuals with lower literacy skills evaluate print-based health information, such as pamphlets found in health clinics, waiting rooms and public spaces¹. To address these limitations, a pilot study was conducted with individuals who have low literacy skills to investigate the following:

- RQ1. How do individuals with low literacy skills evaluate health information?
- RQ2. What criteria do these individuals use to evaluate health information?

¹ Individuals with low literacy skills have been found to rarely use health resources online and to rely mostly on print-based sources (U.S. Department of Health and Human Services, 2008).

3 Methods

The method of data collection for this pilot case study used triangulation, including:

- (a) a short demographic survey questionnaire
- (b) an information evaluation task
- (c) a follow-up interview

Since the unit of analysis was the process of evaluation of health information, and no clear or single set of outcomes was expected, the exploratory case study method was selected as an appropriate way to gather data related to this process (Baxter and Jack, 2008).

Because of the unique challenges of conducting research in third-party sites and of working with study participants of limited literacy skills, the study design considered the cognitive load of the evaluation tasks for participants who have difficulty reading, as well as the potential perception that the participant was being tested on her reading abilities or medical knowledge. In addition to designing tasks that are cognitively appropriate for the participants, this type of study should address the bias inherent in the different power dynamics at play in the research context, including the power structures embodied by the research site itself. The purpose of incorporating this set of considerations into the research design is to preserve the quality of the data collected and the validity of findings.

3.1 Participants

The study used theoretical sampling by focusing on the patient population of Diaspora Community Services, which operates a health clinic in a community with a high incidence of poverty, unemployment, and low levels of education, including individuals living in subsidized housing, and who are mostly immigrants or individuals of African American, West Indian or Latino descent (Diaspora Community Services, 2013). Important considerations when working with members of this community include: their limited free time in which to participate in the study, limited means of transportation to and from the study site, as well as limited education and reading skills.

3.2 Selecting Research Materials

The documents used in the evaluation task included one 6-page brochure and one 1-page fact sheet related to diabetes management and prevention, a topic chosen due to the prevalence of diabetes among adults in the United States (American Diabetes Association, 2015). Consequently, participants might have already been familiar with the topic regardless of their own health status, and they therefore might be more engaged with judging information quality rather than learning about a new topic, which might affect results.

3.3 Evaluation Task

The evaluation task was loosely modeled after usability testing methods. Because the goal of usability testing is not to test participants, but rather to evaluate a product in use (Lewis, 2006), this method is a useful model for the consumer health information evaluation task in this pilot study. The task was to judge the information quality of a document. Participants were instructed to mark up the documents with colored pens to designate “good,” “helpful,” or “useful” document features (green pens) and “bad,” “confusing,” or “not useful” document features (red pens). In this way, the researcher hoped to minimize their perception that they were the focus of the evaluation and, instead, attempted to confer authority on them as judges of information quality.

3.4 Semi-Structured Interviews

After completing the evaluation task, the researcher conducted a semi-structured interview in which the participant pointed out features of each document she found useful or not, paying special attention to portions of the documents the participant had marked with either red or green pens, and noticing interesting markings such as participants adding their own written content to the documents. The researcher was also interested in specific features, such as vocabulary, statistics, and the use of charts, and therefore asked questions about these, such as the individual’s perception of the different statistics cited in the documents, her level of familiarity with “gestational diabetes,” “pre-diabetes,” and “A1C.”

3.5 Survey Questionnaire

To avoid overwhelming the participants, the survey questionnaire only included 7 short demographic questions printed on a single sheet of paper in 14-point Arial font to make them easier to read. The researcher read these instructions aloud to each participant and also offered to read the survey questions and record the answers for them if they so desired.

4 Results

This pilot study used method triangulation to enrich data collection. Not only does this yield rich data, but part of the data collected includes the identification of specific linguistic features of health documents that affect the way an individual with limited literacy skills evaluates consumer health information, such as design features, participants’ prior knowledge of the topic, the potential use of the documents, and factors related to comprehension like term usage and the interpretation of statistical figures and bulleted lists. To ensure the validity of the findings and the quality of the data collected, special data integrity measures were implemented during the research design process. These include designing tasks and instructions for participants that are cognitively appropriate, as well as addressing researcher and institutional bias, such as the power imbalance created by the research site.

Two of the participants in this pilot study demonstrated some domain expertise by identifying pieces of information they felt were missing from the documents or that seemed confusing based on information they had either seen on TV, learned from friends and family who are diagnosed with diabetes (second-hand knowledge), or otherwise previously known. For instance, when reading a section of a brochure discussing symptoms associated with diabetes, P1 added the phrase, “Weight Gain,” as an additional bullet item and mentioned during the interview that she knows from past experience that diabetes also causes weight gain, so she “knows it’s also a symptom.”

Participant P2 also added a bullet item, the word, “Pain,” and explained that she has seen television commercials in which managing foot pain is also part of diabetes care. This method of data collection is potentially empowering, allowing participants to take on the role of expert when judging information quality.

The examples mentioned above are instances of the participants’ mastery of life which, according to ELIS, provide insight as to individuals’ way of life (Savolainen, 1995). Mastery of life is an important concept in the ELIS framework as it makes manifest the way in which social factors such as values direct or structure actions. Participants in this study exhibited an active mastery of life when they identified, resolved, corrected, and evaluated missing or incongruent information in the consumer health information documents they were tasked with evaluating.

5 Limitations

Because the study was conducted at a health clinic, it is possible that the participants might have felt some bias during the research session due to their pre-existing relationship with the clinic. While acknowledging the benefits of collaborating with a third party who has access to qualified participants, a more neutral site might be better suited for the actual study itself. Another challenging outcome was the perceived difficulty of the task for some participants due to their level of interest, motivation or reading ability. Though this can never be fully erased when conducting a user study such as this, the researcher must be attentive to the participant’s level of effort during the task since a task’s perceived level of difficulty can diminish the participant’s motivation and, therefore, hinder task completion. A related issue is a participant’s pre-existing health conditions, such as problems with vision that might affect her reading ability. One participant in this pilot case study, for instance, self-disclosed having problems with her eyesight, leading her to mark in red ink entire sections of the documents that were printed in a font size too small for her to see.

6 Conclusion

Because the case study method presented here focuses on document features rather than on assessing the skills of participants, this method can also examine the evaluation process of other adults who might have trouble reading these same documents as well, such as English language learners. Considering the long history and vested interest of libraries in providing literacy services for communities in need, developing sound methods for working with special populations could significantly broaden the field’s understanding of the unique experiences, challenges and ways of knowing of marginalized and vulnerable groups.

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