

eHealth and Health Literacy: A Research Methodology Review*

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The development of e-health may provide powerful tools to improve health, but users' health literacy plays a role in their ability to make the most of e-health applications. This study reviewed research focused on e-health and health literacy, using content analysis to assess 95 articles from 2000 to 2010 to provide an overview of work done in this emerging field. Articles were coded for use of theory, research methods, and clarity of reporting study results. Findings indicate a lack of theory-driven design and evaluation of e-health applications, low use of established general health literacy measures, and interdisciplinary work with somewhat limited contributions by communication scholars. Implications for advancing this field of research are discussed.

Key words: health, literacy, content analysis, health measures, health theory.

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The Internet has provided a powerful platform for changing the way people deal with health issues. More than three-quarters of Americans now have access to the Internet, with up to 80% of them having used the platform to acquire health information (Kuehn, 2011). Health information provided via the Internet can range from educational interventions (Glasgow et al., 2011), to online support groups (Eichhorn, 2008), to information about do-it-yourself genetic testing services available to the general public (23andMe Inc., 2010). Speaking broadly, e-health – the delivery of health information and services via the Internet and related technologies (Eysenbach, 2001) – provides a virtually limitless set of tools and opportunities for improving users' health.

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The full potential of e-health to improve users' health, however, may be limited by users' health literacy. Health literacy – the ability to obtain, process, and act appropriately on health information – is a major contributor to health outcomes (Ad Hoc Committee on Health Literacy, 1999; Nielsen-Bohlman, Panzer, & Kindig, 2004). Problems associated with low health literacy, such as difficulty following medication instructions or understanding patient information brochures, are common – between one third and one half of U.S. adults have low health literacy (Ad Hoc Committee on Health Literacy, 1999; National Center for Education Statistics, 2003; Nielsen-Bohlman et al., 2004). The concern is even more pronounced among ethnic minorities, the elderly, and those of lower socioeconomic status (Ad Hoc Committee on Health Literacy, 1999; Nielsen-Bohlman et al., 2004), the same groups that often suffer from health disparities and chronic health conditions.

One of the ongoing challenges in this area of research is effectively measuring health literacy—a complex concept that is more than simple reading ability. A number of established measurements of general health literacy have achieved widespread use, including: the Newest Vital Sign (NVS) (Weiss et al., 2005), the Test of Functional Health Literacy in Adults (TOFHLA) and Short Test of Functional Health Literacy in Adults (STOFHLA) (Parker, Baker, Williams, & Nurss, 1995), and Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993). One of the practical challenges in assessing health literacy is that the instruments are often orally administered, which becomes particularly problematic when conducting research online. Table 1 provides additional details about each health literacy measure, including example articles in the content analysis that used each health literacy assessment.

In addition to the development and use of health literacy measurements, the availability of online health information sources and effective intervention strategies has improved in recent years. E-health interventions have the potential to be more engaging than traditional patient information brochures due to the ability to use more audiovisual information (Campbell, Honess-Morreale, Farrell, Carbone, & Brasure, 1999), and such interactivity can enhance learning (Gustafson et al., 2005; Tremayne & Dunwoody, 2001). Interventions designed specifically to meet the needs of low health-literate audiences have proven to be effective both for the intended low health-literate users as well as those with higher health literacy (Mackert, Love, & Whitten, 2009; Mackert, Whitten, & Garcia, 2008). Formative research has also begun to focus more on how lower health-literate users make use of the Internet, including creative uses of general purpose tools (e.g., using a Google Image search to look for information about a rash) and heuristics for determining online information accessibility (e.g., websites with a .edu domain are likely to be too complex) (Mackert, Kahlor, Tyler, & Gustafson, 2009). Such work is crucial to guide the development of e-health interventions that can fully meet the needs of users with varied levels of health literacy.

Healthy People 2020, a federal plan for improving the health of all Americans, includes objectives related to health communication and health information technology which include improving health literacy, increasing the number of people using electronic personal health management tools, and increasing the proportion of online health information seekers who report easily accessing information (U.S. Department of Health and Human Services, 2011). The fact that these goals fall into one topic area recognizes the linkages between health literacy, health communication, and e-health—linkages this research was designed to investigate.

As researchers and practitioners develop e-health interventions, there is ample evidence to believe that use of theory in the design and evaluation can improve the efficacy of the interventions and outcomes of users (Glanz, Rimer, & Lewis, 2002). Given the interdisciplinary nature of this work, relevant theories might include: health communication theories such as the Health Belief Model (Becker, 1974), information systems theories such as the Technology Acceptance Model (Davis, 1989), or conceptual models of health literacy (Zarcadoolas, Pleasant, & Greer, 2005). Consistent and rigorous

use of theory could help improve the ability of researchers working at the intersection of health literacy and e-health to learn from others' efforts and contribute to improved user health outcomes.

To continue advancing research into how e-health can best improve outcomes for low health-literate patients, it is crucial to examine the methods and trends in the field and consider how research in this area might be improved. To date no overview of measures and methodologies focused specifically on the intersection of health literacy and e-health research have been conducted. The

Table 1 Health Literacy Measures

Health Literacy Measure	Items	Range of Possible Scores	Example Articles in Sample Using this Measure
Newest Vital Sign (NVS)	A nutrition label is presented with a six-item survey	Scores range from 0–6. 0-3: Possibility of limited literacy 4-6: Almost always indicates adequate literacy	Donelle, L., Hoffman-Goetz, L., Gatobu, S., & Arocha, J.F. (2009). Comprehension of Internet-based numeric cancer information by older adults. <i>Informatics for Health & Social Care</i> , 34(4), 209–224. Zoellner, J., Connel, C., Bounds, W., Crook, L., & Yadrick, K. (2009). Nutrition literacy status and preferred nutrition communication channels among adults in the Lower Mississippi Delta. <i>Preventing Chronic Disease</i> , 6(4), 1–11.
Rapid Estimate of Adult Literacy in Medicine (REALM)	Three lists of 20 words are presented, and participants are asked to read the words aloud or say “blank” if they cannot pronounce the word	Scores range from 0–66. 0-18: Third grade and below; will not be able to read most low-literacy materials; will need repeated oral instructions, materials composed primarily of illustrations or audio or video tapes 19-44: Fourth to sixth grade; will need low-literacy materials, may not be able to read prescription labels 45-60: Seventh to eighth grade; will struggle with most patient education materials; will not be offended by low-literacy materials 61-66: High school; will be able to read most patient education materials	Peterson, N.B., Dwyer, K.A., & Mulvaney, S.A. (2009). Computer and Internet use in a community health clinic population. <i>Medical Decision Making</i> , 29, 202–206. Price-Haywood, E.G., Roth, K.G., Shelby, K., & Cooper, L.A. (2010). Cancer risk communication with low health literacy patients: A continuing medical education program. <i>Journal of General Internal Medicine</i> , 25(Suppl 2), 126–129.

Table 1 Continued

Health Literacy Measure	Items	Range of Possible Scores	Example Articles in Sample Using this Measure
Test of Functional Health Literacy in Adults (TOFHLA)	A combination of 50 reading questions and a 17-question assessment of number skills	Weighted scores range from 0–100. 0–50: Inadequate Functional Health Literacy (unable to read and interpret health texts) 60–74: Marginal Functional Health Literacy (difficulty reading and interpreting health texts) 65–100: Adequate Functional Health Literacy (can read and interpret most health texts)	Maybe, J.K., & Giordano, T.P. (2007). Internet use among low-income persons recently diagnosed with HIV infection. <i>AIDS Care</i> 19(9), 1182–1187. Sox, C.M., Gribbons, W.M., Loring, B.A., Mandl, K.D., Batista, R., & Porter, S.C. (2010). Patient-centered design of an information management module for a personally controlled health record. <i>Journal of Medical Internet Research</i> , 12(3), e36.
Short Test of Functional Health Literacy in Adults (STOFHLA)	Abbreviated version of the TOFHLA, includes 36 reading questions and no number skills assessment	Scores range from 0–36. 0–16: Inadequate Functional Health Literacy (unable to read and interpret health texts) 17–22: Marginal Functional Health Literacy (difficulty reading and interpreting health texts) 23–36: Adequate Functional Health Literacy (can read and interpret most health texts)	Choi, J., & Bakken, S., (2010). Web-based education for low-literate parents in Neonatal Intensive Care Unit: Development of a website and heuristic evaluation and usability testing. <i>International Journal of Medical Informatics</i> , 79, 565–575. Shieh, C., Mays, R., McDaniel, A., & Yu, J. (2009). Health literacy and its association with the use of information sources and with barriers to information seeking in clinic-based pregnant women. <i>Health Care for Women International</i> , 30, 971–988.

current review of current e-health and health literacy research includes issues such as the use of theory in guiding intervention design and evaluation, research methods utilized, and clear reporting of study results. This research project was therefore designed to answer the following research questions:

RQ1: What is the incidence of theory in e-health research related to health literacy?

RQ2: What percentage of studies clearly report on specific study details, such as hypotheses and research questions, study location, and number of subjects?

RQ3: What methods are used in conducting research into e-health and health literacy and how are results reported?

The remainder of this manuscript outlines study methods, reports on the findings of this investigation, and discusses the implications of these findings for the future of research in this field.

Methods

A content analysis was executed to determine the occurrence of several key aspects in peer-reviewed journal articles relevant to the research fields of e-health and health literacy. This method is commonly used in health-related literature, and, according to the Cumulative Index to Nursing and Allied Health Literature, an increasing number of articles are making use of this technique each year (Hsieh & Shannon, 2005). A content analysis typically involves establishing key research questions, choosing a group of data, describing target themes, designing a coding scheme, applying the codes to the selected content, evaluating the validity of the coded data, and then executing the analyses (Kaid, 1989). The full sample of articles – the unit of analysis for this study was the article – was coded by three graduate student coders, with each article read and coded by two individuals. After independently coding articles, the coders met to resolve differences in their coding, discussing discrepancies to arrive at a final decision for all variables on each article – ensuring agreement between coders (Riffe, Lacy, & Fico, 2005). This final, resolved data set was used for analysis.

Study Sample

The first step in arriving at a study sample was defining a search strategy. It was determined that full text searches with the keyword *health literacy* combined with *e-health*, *telemedicine*, *telehealth*, *online*, *website*, and *Internet* in succession would result in a range of articles related to the research area of interest. EBSCOhost was used to search a total of 70 databases, including AcademicSearch Complete, CINAHL, Communication and Mass Media Complete, ERIC, Health Source, MedicLatina, MEDLINE, and PsycINFO. These databases are widely used and index a substantial collection of articles relevant to the current study. This approach of using keyword searches of academic databases has been used successfully in previous literature reviews (Whitten, Johannessen, Soerensen, Gammon, & Mackert, 2007), and it is a thorough method for implementing a refined search of academic publications that is narrowly focused on the relevant topics of interest.

The purpose of this investigation was to determine how researchers are developing or evaluating interventions while considering the health literacy of users. Therefore, additional inclusion criteria for the study sample included: *peer reviewed journal articles* (i.e., no theses or dissertations, conference papers, books, or self-published works) and *included actual subjects* (i.e., no assessments of the readability of a website or other intervention). The combination of the search strategy outlined above and study inclusion criteria resulted in a final study sample of 95 articles ($N=95$).

Coding Scheme and Data Analysis

A coding guide used in a larger and more general review of telemedicine literature was adapted for the specific needs of the current study (Whitten, Johannessen, Soerensen, Gammon, & Mackert, 2007). This preliminary coding guide was then reviewed by the lead author and three coders to determine what items might need to be added or changed to reflect the focus of this project on issues related to health literacy in e-health research. A draft coding guide was used to evaluate a subsample of 10 test articles, at which point the coding guide was revised to clarify issues that arose in the practice coding of the 10 sample articles.

The coding guide was designed to address all three research questions, including items related to use of theory and conceptualization of health literacy, items regarding the clear description of

study details, and items related to study methods and reporting of results. Of particular interest was the use of the established general health literacy measures, given the need for standardized measurement of health literacy to improve the ability of researchers working in this area to learn from others' work and understand who participated in the projects. For this project "general health literacy measures" were defined as validated scales intended to assess general health literacy; this would not include single-item assessments and screeners, assessments of electronic health literacy, or domain-specific health literacy measures. The final coding guide is provided in Figure 1.

Results

All studies included in the sample were published during and after 2000, with fewer older studies (one in 2003, six in 2005, and four in 2006) leading toward a trend of more research in this area (14 in 2007, 10 in 2008, 24 in 2009, and 36 in 2010).

Most of this research was completed within the context of teams, as the average number of authors on a manuscript was 4.3 ($SD=2.2$). Of the articles that reported author credentials ($n=66$), the vast majority included a Ph.D. (77.3%), with the other most common author credentials including M.D. (33.3%), M.P.H. (22.7%), and R.N. (22.7%). For those articles that provided the affiliation of the authors ($n=81$), most came from a department related to general health or medicine (63.0%). The remaining authors were affiliated with departments such as nursing (17.3%), information or decision making (17.3%), mental health (16.0%), communication (7.4%), engineering or computer science (2.5%), and other (13.6%). Notably, some authors were associated with multiple academic departments, which is reflected in this category breakdown of percentiles.

The included articles covered a breadth of health topics, with mental health (15.8%), cancer (9.5%), and diabetes (9.5%) the three most common contexts. In addition, most publications were in general health and medicine journals (42.1%), followed by information or decision making (21.1%), mental health (13.7%), communication (10.5%), nursing (6.3%), telemedicine (4.2%), and other (2.1%).

RQ1: Incidence of Theory

The overwhelming majority (93.7%) of studies included in this sample did not make use of theory. Moreover, of the articles that did make use of theory, it was more common to utilize the theory in a peripheral manner (4.2%) than as an explicit, core driver of the design and evaluation of the intervention and evaluation (2.1%). This differentiation was made based on whether the study relied primarily upon aspects of a theory for their study (e.g., Lariscy, Reber, & Paek, 2010) or if the study used a theory in a tangential fashion, such as developing stimuli using some principles from the theory (e.g., Choi & Bakken, 2010).

In addition to whether or not articles reported on the use of theory, each study was also coded for its conceptualization of health literacy as a barrier to be overcome in effective communication or as a capacity to be built in participants and intervention users. These were not mutually exclusive concepts, as the same study could conceptualize health literacy in both ways. Almost half of the studies (47.4%) described health literacy as a barrier to be overcome in effective communication (e.g., Austvoll-Dahlgren & Helseth, 2010). Nearly all investigations (88.4%) considered health literacy a capacity that could be developed and improved (e.g., Bell, Patel, & Malasanos, 2006).

RQ2: Reporting Study Details

In addition to theoretical considerations, each article was assessed for the degree to which it clearly reported study details and purpose. Only 15.8% of studies included in this sample provided a clear,

explicit statement of research questions or hypotheses that guided the research. Most studies (57.9%) were primarily focused on evaluating the impacts of interventions, with the remainder explicitly feasibility or pilot studies (40.0%) or something else (2.1%).

The majority of studies (90.5%) clearly reported the total number of study subjects, and in all cases it was possible to determine the location where the study took place. Most were conducted in the

1. Did the study use theory?
 - Yes (Core): use of theory guided intervention design and evaluation
 - Yes (Peripheral): theory mentioned in the literature review or discussion, not explicitly used in the process of designing/evaluating the intervention
 - No
2. If theory was used, which one(s): _____
3. Explicit statement of RQs or Hs?
 - Yes
 - No
4. Major goal of the study:
 - Feasibility/pilot: design and pilot an intervention
 - Impacts/effects: evaluate impact of intervention on users' attitudes, behavior, health outcomes, etc.
 - Other: _____
5. Location (country or countries): _____
6. Subjects:
 - Intervention users: adolescents (under 18), adults (18-64), seniors (65+) (check all that apply)
 - Intervention designers
 - Other: _____
7. Number of subjects clearly stated?
 - Yes
 - No
8. Total number of subjects: N= _____
9. Was the study randomized?
 - Yes
 - No
10. Methods of data collection: (check all that apply)
 - Survey
 - Interview
 - Focus group
 - Observation
 - Psychometric/physiological
 - Other: _____

Figure 1 e-Health and Health Literacy Coding Guide

11. Results presented as: (check all that apply)
 - Quantitative
 - Qualitative
12. Language of participants: _____ (if not stated, assume English)
13. Health literacy measures: (check all that apply)
 - Newest Vital Sign (NVS)
 - Test of Functional Health Literacy in Adults (TOFHLA)
 - Short TOFHLA (S-TOFHLA)
 - Rapid Estimate of Adult Literacy in Medicine (REALM)
 - Other: _____
14. Mean NVS Score:
Based on N: _____
15. Mean TOFHLA Score:
Based on N: _____
16. Mean S-TOFHLA Score:
Based on N: _____
17. Mean REALM Score:
Based on N: _____
18. Overall gender breakdown: M _____% F _____%
Based on N: _____
19. Mean Age:
Based on N: _____

Figure 1 Continued.

U.S. (65.4%), with Australia (12.7%), Canada (8.5%), and the United Kingdom (7.5%) the next most common locations. Only two studies included in the sample were conducted in more than one country. Almost all studies were conducted exclusively in English (88.5%), with most of the remaining studies conducted jointly in English and Spanish (8.4%).

RQ3: Research Methods and Reporting Results

A sizable minority of studies included in the sample randomized study conditions (21.1%). Participants included adolescents (18 years and under; 19.0% of studies), adults (18–64 years old; 92.6% of studies), and seniors (65 years and older; 37.9%). A small number of projects (6.3%) collected data from intervention designers.

In terms of data collection methods, surveys were the most common strategy (84.2%), followed by interviews (22.1%), focus groups (13.7%), and observation (6.3%). Almost all studies presented quantitative findings (85.3%), with 24.2% providing qualitative findings. Few studies utilized existing health literacy measures, with the STOFHLA the most common (9.5%), followed by the REALM (6.3%), full TOFHLA (5.3%), and NVS (2.1%). However, the most common strategy for assessing health literacy was a different, “other” measure, with 26.3% of studies using some other assessment of health literacy.

Examples of “other” measures included domain-specific (e.g., cancer, mental health) health literacy measures (9.5%), qualitative assessments (e.g., through interviews) of health literacy (5.3%), the e-Health Literacy Scale (eHEALS; 2.1%), and single-item health literacy assessments/screeners (2.1%); other researchers constructed original instruments based on the health literacy literature or designed by health literacy experts. Of the 22 articles that implemented one of the established measures of general health literacy, 16 reported the mean established through the given health literacy measure. Those studies utilizing standardized measures the average health literacy scores were 3.3 ($SD=2$) on the NVS, 87.6 ($SD=8.8$) on the TOFHLA, 28.4 ($SD=6.1$) on the STOFHLA, and 48.4 ($SD=7.6$) on the REALM. These average scores indicate a likelihood of low health literacy as measured by the NVS, adequate health literacy as determined by the TOFHLA and STOFHLA, and 7th-8th grade reading ability according to the REALM.

The mean number of participants in these studies was 522.3 ($SD=1,567.5$), a number that is skewed by several large studies including one that had over 14,000 participants; the median sample size was 143. For those studies that reported mean age and gender of participants, the average age of participants was 45.7 ($SD=14.3$) and projects included more females (57.9%) than males (42.1%).

Discussion

There is great potential for e-health tools and interventions to help patients improve their health, but the full power of e-health can only be realized if such technology is designed and implemented with users' health literacy in mind. The purpose of this investigation was to highlight trends and potential issues in e-health research that included some recognition of health literacy. Results suggest that research in this area could be improved in a variety of ways that would strengthen the field and improve the ability of researchers to conduct their own work and learn from each other. First, the implementation of surveys was common across the articles reviewed for the current study. Although this parallels findings from more general reviews of applied communication literature (Query et al., 2009), this methodology may not be the most effective for collecting data in the relatively new intersection of research on health literacy and e-health. It is important to emphasize the increased use of more exploratory data collection techniques for the purpose of investigations such as these. Also, the lack of theoretical grounding of research in this area is one major issue of concern, of course, and it is consistent with broader telemedicine and e-health reviews (Whitten, Johannessen, Soerensen, Gammon, & Mackert, 2007). Given that integration of theory in the design and evaluation of interventions can increase the impact of interventions and dissemination of results (Glanz et al., 2002; National Cancer Institute, 2004), this is an obvious and crucial aspect of e-health research in need of improvement. Theories that might guide effective research in this area include health communication theories, information systems research, and emerging conceptual models of health literacy.

Although few investigations included in the present study relied upon theory, many utilized a range of methods, including focus groups, interviews, surveys, and observations—which is appropriate given the differing goals of various research projects. In contrast, the lack of use of established general health literacy measures represents another major concern, as only a small number of studies utilized the NVS, TOFHLA, STOFHLA, or REALM. More studies used an “other” measure, which may have been an instrument created specifically for an individual project or a modified version of another instrument, but this reduces the ability to generalize findings and replicate lessons learned. Additionally, mean reported scores for health literacy measures indicate that participants in these studies were often quite health-literate, suggesting a need to actively recruit lower health-literate participants to improve the ability of research to investigate how e-health interventions can better reach these at-risk

populations. These findings suggest a need for both use of established general health literacy measures and development of health literacy assessment tools that are designed to be administered remotely online; this would advance research in this area beyond relying on single-item screeners or creating assessment tools from scratch for individual projects, even when such screeners or assessment tools are validated against general health literacy scales such as the REALM, TOFHLA, or NVS.

While the research examined in this study appeared to be quite interdisciplinary, there seems to be an underrepresentation of scholars affiliated with communication departments and schools. Given the expertise of communication researchers in relevant domains—designing clear messages, information processing, persuasive communication, health communication theories, etc.—increasing the contribution of communication academics to the design and evaluation of e-health interventions will be crucial to ensuring these applications effectively reach low health-literate audiences.

In considering implications for future research, it is important to first recognize the limitations of this review. The study sample was limited to articles published in English, so it may not accurately reflect research in this area that has been conducted and published in other languages. It is also possible that the search of databases that yielded this study sample may have missed relevant articles that failed to use the specific terms that were used in this search strategy. Finally, a lack of details included in the studies themselves may mean that values reported in the results (e.g., mean health literacy scores) may not accurately reflect the true mean value for the entire field.

Even with these potential limitations, study results point to clear ways to improve research into e-health and health literacy, including how such work is reported. There is a definitive need for increased use of theory in the design and evaluation of interventions. Just as importantly, there is a need to make use of more established and widespread general health literacy tools. This will increase the ability of researchers to compare results, and will help to measure the size of communication barriers and to assess pre- and post-intervention changes in health literacy. There is also a clear need to reach out to lower health-literate individuals, improve the clarity and consistency of reporting study results, and be clear on the research questions and hypotheses that studies are intended to address.

Health literacy has received increasing attention as a driver of health outcomes, so it comes as little surprise that many studies have begun to consider health literacy as it relates to e-health. Research in this field could help improve the use of e-health to effectively provide important health information to lower health-literate populations, while also helping to improve their skills for finding, understanding, and making appropriate use of health information. This exploratory research was intended to highlight potential strengths and weaknesses of the research that has been conducted at this interface of e-health and health literacy research, to improve the state of the field and help advance the conversation.

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