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Health Literacy and Informatics in the Geriatric Population: The Challenges and Opportunities

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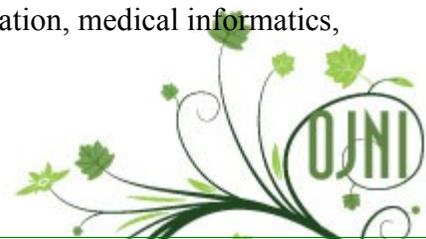
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Abstract

Individuals at highest risk for low health literacy, and with the most chronic conditions and cognitive challenges, are over the age of 65. Those with the greatest need for health care are the ones least able to read and comprehend the information needed to function effectively in the healthcare system. By focusing on information creation, accessibility and usability, healthcare informatics can play a large role in increasing literacy levels. The healthcare profession has a responsibility to identify those at risk and assure that the geriatric population has the necessary understanding to participate in their own healthcare.

Keywords: Health literacy, healthcare informatics, geriatric population, medical informatics, patient education





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Health care reform is high on the list of the Obama administration's initiatives for this country. Comprehensive reform must include the issues of quality, equity, and patient-centeredness and their impact on health care (*Toward health equity*, 2009). Health literacy, which is the ability to obtain, understand and act on health information for one's own behalf, plays a large role in each of these issues (*Health literacy*, 2004). According to former Surgeon General Richard Carmona, "today, low health literacy is a threat to the health and well-being of Americans and to the health and well-being of the American medical system" (Carmona, 2003).

Health literacy, a problem for consumers of all ages, is included as one of the objectives of the nation's health promotion initiative "Healthy People 2010" (U.S. Department of Health and Human Services, 2000). It is important to understand that health literacy is not defined as whether someone can read. Individuals with adequate literacy skills may have difficulties with the comprehension of medical terms, concepts, and instructions. Misunderstandings occur when there is a gap between the complexity of the information and a person's ability to understand and use that information. The over 65 population and those with low incomes are considered at highest risk for low health literacy, poor health, and early death (*Health literacy*, 2004). Healthcare informatics has a role to play in quality, equity, and patient-centeredness through information creation, accessibility, and usability, with the goal of a positive effect on patient actions and outcomes.





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Overview

Distinguishing between the concepts of literacy and health literacy is the first step in understanding the profound consequences of low health literacy. Literacy is necessary to use written materials in order to function in society and to fulfill one's goals and potential in life. It is a skill set of reading, writing, basic mathematics, speech, and speech comprehension (*Health literacy*, 2004). Health literacy requires a more complex set of skills that encompass print literacy (reading and writing), oral literacy (listening and speaking), numeracy (understanding and work with numbers), cultural and conceptual knowledge. Health literacy enables consumers to use information to make educated choices that improve health and reduce risks (Zarcadoolas, Pleasant, & Greer, 2003). Even for individuals with adequate or proficient health literacy, it is difficult to navigate through the complicated and intricate maze of the U.S. healthcare system. The healthcare system presumes adults have adequate literacy.

When low health literacy is not identified, the opportunity for choosing preventive over curative treatment is compounded and may be lost. Examples of daily challenges faced by Americans include the analysis of risk factors in television advertisements for prescription medications, healthy diet decisions based on food and product labels, the impact of air quality reports for an emphysema patient, the choice of a health care plan, completing a health insurance form, comprehending an informed consent document, or understanding a drug label's instructions.





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Various governmental agencies and corporations have taken the lead in highlighting the presence of and manifestations of limited health literacy in the American population. The National Library of Medicine lists, on their website, a bibliography of the literature from 1998 through 2003 containing 651 citations. "Health Literacy: A Prescription to End Confusion" (2004) is a book published by the Institute of Medicine. The Agency for Healthcare Research and Quality (AHRQ) has supported several research studies on the topic. The National Institutes of Health has listed on ClinicalTrials.gov 17 open studies currently recruiting participants for literacy projects. The pharmaceutical company, Pfizer, is promoting an "Ask Me 3" campaign, as part of the Partnership for Clear Health Communication, to educate providers on how to improve communications with patients ("Pfizer clear health," 2008).

The numbers

The National Assessment of Adult Literacy (NAAL), sponsored by the National Center for Education Statistics, assessed health literacy as well as English literacy in American adults, aged 16 and older, in 2003. The survey assessed the four levels of health literacy as below basic, basic, intermediate, and proficient. It takes intermediate skills to be able to read instructions on a prescription label and to determine what time to take the medication. A large percentage of Americans performed below the intermediate level. Fourteen percent of adults, representing 30 million Americans, had below basic health literacy, and 21%, 47 million, had basic skills ("National





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assessment of adult literacy," 2003). The numbers for older adults are dramatic. Thirty nine percent, almost two-fifths, of those over the age of 75 had below basic health literacy and 23% of the 65-75 group were below basic. Fifty nine percent of the over 65 population had basic skills. The significance of these numbers is illustrated with the realization that Medicare beneficiaries fill an average of 27 prescriptions per year and see eight different physicians (*Standardizing medication labels*, 2008).

Testing for literacy

Two tests used to assess health literacy are Rapid Estimate of Adult Literacy in Medicine (REALM) and Test of Functional Health Literacy in Adults (TOFHLA) (*Health literacy*, 2004). REALM consists of 66 words to test reading ability, but not comprehension. It can be administered in three minutes. TOFHLA, used to test comprehension, has two versions, one lasting 22 minutes and a shortened 12-minute version. Both English and Spanish versions are available. However, neither instrument measures oral communication or writing skills. While it is vital for practitioners to know patients' health literacy levels, the practicality of conducting such time intensive tests in a clinical setting, with no chance for insurance reimbursement, is questionable. Additionally, busy healthcare settings, such as clinics, pharmacies and physician offices cannot offer a private, embarrassment-free environment for the patient.





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Geriatric population

In our present day system, patients are being asked to take more responsibility for their own health. The leading causes of illness, death and disability in this country are chronic conditions, such as diabetes, hypertension, and chronic obstructive pulmonary disease. Forty four percent of those with chronic conditions have more than one (*Crossing the quality chasm*, 2001). Successful care of chronic disease incorporates self-management as a collaborative process with a healthcare provider. Unfortunately, several studies indicate that patients remember and comprehend half of what they have been told by their physicians (*Health literacy*, 2004). For those with limited literacy abilities, the challenges to understand, remember, and interpret instructions may be too great to overcome. Individuals at highest risk for low health literacy, and with the most chronic conditions and cognitive challenges, are the elderly. Those with the greatest need for health care are the ones least able to read and comprehend the information needed to function effectively in the healthcare system.

Declines in cognitive function, without the presence of dementia, have been attributed to the marked prevalence of low health literacy in the geriatric population. As individuals age, their ability to perform tasks requiring effortful processing of information is impaired (Baker, Gazmararian, Sudano, & Patterson, 2000). Healthcare instructions and recommendations are often given verbally, requiring the individual to rely on memory. The comprehension of written materials is a complex cognitive task. Working memory or short-term memory is necessary for text comprehension, and





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declines with age. Seniors may also have difficulty making inferences from information presented to them. The processing of new information is particularly difficult in the face of declining working memory and attention deficits.

Studies cannot agree on whether health literacy is associated with the presence of chronic diseases (Baker et al., 2000). The relationship between years of schooling and literacy is not clear. Some studies show a link, others do not (Cutilli, 2007) (Gazmararian et al., 1999). One study showed 30% of college-educated seniors in a retirement community had poor comprehension of written healthcare information (Benson & Forman, 2002).

A prospective cohort study of seniors living in the community examined literacy levels as a prediction of mortality (Baker, Wolf, Feinglass, & Thompson, 2008). The authors found that both reading comprehension and cognitive abilities can predict mortality. Those with inadequate and marginal health literacy were more likely to die than those with adequate literacy.

Sensory impairments, such as eyesight and hearing are common in this population. A decrease in visual acuity makes it difficult to read, as hearing deficits makes it difficult to hear and understand verbal instructions. The noisy environments of hospital or clinical settings reduce the ability of many seniors to understand new information. Oral communication deficits in the geriatric population contribute to impaired health literacy. Members of this age group may not question or challenge their healthcare providers. If the patient is passive or seems uninterested, inappropriate treatment decisions





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may be made, especially if an accurate medical history cannot be obtained from the patient.

A huge area of concern is the ability of this group to fully comprehend their medications. The geriatric population consumes more than 30% of all prescription medications, often simultaneously taking multiple medications (Larsen & Martin, 1999). This volume of drug use presents a risk for medication misuse or non-adherence, which may lead to adverse drug events, the potential for falls, re-hospitalizations, and addiction (Alemagno, Niles, & Treiber, 2004). Annually, 1.9 million adverse drug events are estimated to occur among 38 million Medicare patients, with approximately 10% life threatening or fatal (Gurwitz et al., 2003). Limited health literacy plays a significant role in adverse drug events. One area of concern is prescription drug labels that do not meet acceptable design standards for patients with limited literacy (*Standardizing medication labels*, 2008). The ability to understand what to take, why, when and how to take medications is impaired in those with basic or below basic health literacy skills.

Every year, Medicare Part D patients need to choose a new prescription plan provider. Seventy three percent of recipients felt that the prescription plan benefit was too complicated, as did 91% of pharmacists and 92% of physicians (Gruber, 2009). Gruber's study showed that patients were not choosing the most effective plan and stayed with the same one each year, rather than analyzing alternatives that might be more cost efficient. The daunting process involves going through Medicare's database of prescription drug insurers on the Internet or telephone, inputting one's list of





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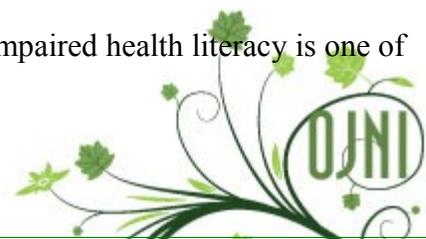
drugs, and then assessing which plan of over 100 provides the best drug prices. If over 90% of professional healthcare providers find the process too complicated, the literacy-compromised senior is completely lost.

Costs

Low health literacy has a financial cost to the healthcare system. While a causal relationship between literacy and health cannot be proven, it has been shown that there are more preventable hospital admissions, higher use of emergency services, less use of preventive healthcare services, and less health-promoting behaviors in those individuals with limited health literacy skills (Howard, Gazmararian, & Parker, 2005) (*Health literacy*, 2004). However, research has not established a valid cost figure for the impact of limited health literacy.

The role of informatics

The American Medical Informatics Association (AMIA), at their 2003 Spring Congress, defined underserved populations as “those that specifically receive fewer health care services than required for actual or potential health care problems” (Chang et al., 2004, p. 449). This definition identifies those populations that suffer from disparities in health outcomes and could benefit from better access to relevant health information resources and support. Impaired health literacy is one of





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the barriers to health information access in the underserved populations. Using AMIA's definition, the geriatric population with limited health literacy qualifies as underserved. The challenge is how to use informatics to enable this population to achieve parity in the healthcare system.

The term "digital divide" describes the difference in opportunities available to those with access to information technology as compared to those who do not. Seniors, for the most part, are on the wrong side of the digital divide and need special consideration. In 2004, 22% of Americans 65 and older used the Internet (Fox, 2004). They are predominantly white, highly educated, and most often looking for online health information. While the number of seniors using computers and the Internet is still relatively low, they are not technophobic, in spite of anxiety and lack of comfort. A positive training experience is the key to positive attitudes, confidence and comfort as well as perceived usefulness of the technology (Czaja & Lee, 2007).

For those seniors who use the Internet, challenges remain. One study found that only 10 out of 1000 websites were accessible for adults with limited health literacy (*Health literacy*, 2004). Age-related changes in vision and cognition require websites designed with larger typefaces, the ability to enlarge type, simple navigation, optimal contrasting colors, and optional audio files describing terms or definitions. Declines in motor capabilities make keyboard actions and mouse control difficult.

Solutions provided by informatics applications should not depend on computers. Information needs to be understandable in any form and any medium. The amount of information that needs to be





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conveyed to patients by their providers cannot occur in the limited time of an office visit. If a patient has impaired health literacy, that office visit may offer even less useable information. Supplemental written materials, including graphical content, are valuable when understood by their intended audiences. Disease outcomes in low literacy patients show improvement if educational materials are written at an appropriate level (Cutilli, 2007). Unfortunately, most information is written at too high an educational level. Averages of tenth grade or above reading levels prevent a vast majority of the geriatric population from taking advantage of the materials.

Three approaches to simplifying written information are text simplification, structure simplification, and text visualization (LeRoy, 2008). Various measures, such as Flesch-Kincaid and SMOG, are available to analyze text reading levels (Aldridge, 2004). They assign reading levels by measuring syntax, word counts, word length, and syllable count. By changing grammar and the complexity of sentence structure, reading levels can be lowered. However, not all documents can be simplified. Some material is complex and requires other means to increase comprehension. Structure simplification provides a summary or preview of a document in either text, graphical, or a combination that conveys enough information to act as a substitute for the original. Text visualization provides a graphical representation of pertinent information.

Informatics can be used to enhance the functionality of the one piece of equipment in most





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every home – the telephone. The state of Massachusetts is testing a system that uses computers to make interactive phone calls to remind patients to make appointments for mammograms, cancer screenings, and influenza immunizations (Michaelson, 2007). Once the appointment is scheduled, follow up calls are made as reminders. The computer speech can be modified to appeal to different ethnic groups. A female voice will call about a mammogram and if the recipient is of Indian descent, the voice will be Indian, thereby making the appeal more personal.

Declines in cognitive function in the elderly and the complexity of tasks involved in healthcare require an examination of the role of cognitive science in informatics. Cognitive science provides a framework for understanding the human factor in technology by highlighting the usability and learnability of information systems for the end user (Patel & Kaufman, 2006). By understanding the processes of the elderly with limited health literacy, interventions incorporating optimal systems and materials can be designed. Cognitive walk-throughs are valuable tools to evaluate the processes of a user as a task is performed (Patel & Kaufman, 1998). A real-time cognitive walk-through, or a virtual one, after interviews with end users and with specific focus on the limited health literate senior performing different tasks, has the potential to find the particular point when an individual falls behind while navigating the healthcare system. This data can provide the framework for discovery of the interventions that create the optimal blending of informatics with the health literacy problems of the geriatric population.





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Conclusions

While there is a consistent call in all the research for yet more research, there is a notable shortage of data on the intersection of health literacy, the elderly, and informatics.

Recognition of the problems of health literacy is a first step. Solutions to the problems are not as clear. The question to ask is whose responsibility it is to ensure that patients have an understanding of the health information they need to take care of themselves. It would be easy to say that it is the duty of the government or the “health care system.” However, both the government and the health care system are huge, bureaucratic entities that can’t easily find the path to the individual patient. Instead, it is the ethical responsibility of the health care professionals who have patient care responsibilities to identify patients at risk and assure that those patients have the necessary understanding to participate in their own healthcare.

There are dollar costs to the health care system due to limited health literacy; however, there are also human costs. Patients with low health literacy are embarrassed by their limited abilities, rarely ask for help, and develop various strategies to mask their inability to read and comprehend healthcare information. In the short time most providers have to give to their patients, communication and miscommunication abound. It must be understood that health literacy is a shared responsibility. Patients need encouragement from inside and outside of the healthcare system to ask questions, seek information, and be a willing partner in self-care.





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The goal of consumer health informatics is to bridge the distance between patients and health resources by analyzing their needs and preferences for accessible information (Brennan & Starren, 2006). Combating health literacy in the geriatric population requires a multi-prong approach. Identification of those affected, education of healthcare professionals to the presence of the problem, and more evidence-based research are required to find literacy testing methods and designs for informatics tools so all patients can understand health information.





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