

Forum

Health Literacy Considerations for a New Cancer Prevention Initiative

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Abstract

Cancer prevention efforts are newly focused on the older adult population. Adult literacy and health literacy findings and suggestions can help shape more efficacious health communication strategies and thereby increase the "accessibility" of important health information and the potential for healthful action. National and international surveys of adult literacy skills have consistently offered problematic findings that older adults have more limited proficiencies than do younger working adults and face difficulties using commonly available materials to accomplish everyday tasks. Clinical as well as population-based studies of health literacy similarly find limited health literacy among a majority of U.S. adults and even poorer health literacy among older adults. This is of concern because health literacy studies have established clear links between limited literacy and poor health outcomes as well as diminished participation in activities related to disease prevention. Literacy experts note difficulties associated with abstract concepts and with sophisticated numeracy tasks, both associated with disease prevention. Health literacy findings and insights are important considerations in the development of health messages and materials to promote cancer prevention among older adults.

Keywords: Health literacy, Literacy, Numeracy, Formative research

The availability of accurate health information has always been highlighted as a foundation stone of health education, health promotion, and disease prevention. The 2011 National Prevention Strategy, notes: "people are empowered when they have the knowledge, ability, resources, and motivation to identify and make healthy choices" (National Prevention Council, 2011). A subsequent report, The State of Ageing and Health in America, calls for action to improve the health and well-being of older adults through coordinated efforts in health promotion, health protection, disease prevention, and early intervention programs (Centers for Disease Control and Prevention, 2013). Both reports highlight the importance of health communication, the availability of health information, and knowledge building. Among the recommendations of both reports is that insights from health literacy

studies be integrated into efforts to make information more accessible and communication about key issues related to disease prevention more appropriate. Health literacy studies have been highlighting the need to focus on the *accessibility* of information along with *availability* of information. Unfortunately, studies of doctors' communication skills (Howard, Jacobson, & Kripalani, 2013), of the needs of elderly patients with cancer (Amalraj, Starkweather, & Naeim, 2009) and of available cancer information (Basch et al., 2018; Hoppe, 2010; Neuhauser & Kreps, 2008; Pruthi et al., 2015; Rosenberg, et al., 2016; Tran et al., 2018) indicate that cancer communication has not met the documented literacy needs of the public or of the older adult population in particular.

This discussion focuses on findings from literacy and health literacy studies that can help shape more

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efficacious health communication strategies and thereby increase the match between cancer prevention information and the known literacy issues among older adults. The background section offers a summary of national and international adult literacy survey results and of research finding of links between health literacy skills of patients and health outcomes. This is followed by a discussion of the evolution of health literacy studies and insights for change at multiple levels that could improve cancer prevention communication efforts for older adults. Of specific concern, are the possible consequences of a mismatch between the literacy and numeracy skills of older adults and the cancer related information and resources designed to help them take healthful action and prevent cancer. The discussion builds on the National Prevention Strategy to provide an argument for attention to literacy and numeracy in the development of efficacious health communication strategies for cancer prevention developed for older adults.

Background

Over the past two decades, health literacy emerged as an important consideration for practitioners and policy makers as well as an important variable in health research focused on health outcomes and disparities (IOM, 2004; Koh & Rudd, 2015). The impetus for these health-related studies is located in the findings from the adult literacy surveys in the United States which indicate that half of the U.S. adult population has difficulty using commonly available materials to accomplish everyday tasks (Desjardins, Murray, & Tuijnman, 2005; Kirsch, 1993; OECD, 2013). Of particular interest here is that older adults are consistently found to have even more limited literacy and numeracy skillsindicating problems for full participation in modern life (Brown, Prisuta, Jacobs, & Campbell, 1996; OECD, 2013). Consequently, attention to literacy and numeracy in the development and design of messages, information, and resources for older adults and for all vulnerable population groups is of major importance.

National and International Adult Literacy Surveys

The foundation of health literacy is rooted in the national and international assessments of adult literacy skills begun in the 1990s and repeated in the early 2000s and again in 2011. Long before these literacy surveys in industrialized nations were conducted, it was well established that literacy was a problem in preindustrialized nations where schooling was sparse or limited to a select few. However, the assumption was that literacy was not an issue for those industrialized countries where schooling was universal and mandated. Findings from the initial survey, the 1992 National Adult Literacy Survey (NALS) conducted in the United States and published in 1993, caused shock and dismay and dispelled the faulty belief that universal schooling yielded a highly

literate society. These large-scale surveys of the literacy skills of adults were undertaken to assess readiness to participate in the complex social and economic environments of the 21st century (Tuijnman, 1996). Each participating country agreed to design a sample representing its national population aged 16-65 years (Murry, Kirsch, & Jenkins, 1997). The U.S. sample consisted of 26,000 adults, comprised of a random sample of 13,600 people over the age of 16, an additional 1,000 adults in each of 12 states, and interviews with 1,100 inmates (Kirsch, 1993). The rigorously designed and carefully sampled surveys of 22 industrialized nations in the 1990s were expanded and repeated between 2003 and 2006 (Desjardins et al., Tuijnman, 2005) to include problem solving and numeric skills. The most recent survey, conducted in 2011, was further expanded to include use of technology (OECD, 2013).

Designed as a 90-min at-home interview, the adult literacy surveys focus on people's ability to use an array of commonly available materials related to family life, health and safety, leisure activities, work, finance, and civic society. The materials used in the surveys varied by type, classified as continuous texts (prose) or noncontinuous texts (documents). Some materials include numbers and required one or more quantitative operations. Among the materials, for example, might be a magazine health article, a newspaper editorial, or a description of a community event (continuous texts) as well as a weather chart, sales advertisement, or medicine label (noncontinuous texts, some containing numbers). All materials were rated for level of complexity and difficulty. The tasks participants were asked to undertake with the materials were directly related to how and why people would use the materials-such as finding a final score in a sports article, determining a bias in an editorial, or identifying dosage on a medicine label. All tasks were rated for level of difficulty and complexity as well (Kirsch, 2001).

Analyses and Findings

Analyses of the adult literacy surveys drew on the extensive background information collected and found that literacy skills are related to characteristics such as age and geographic location as well as to social factors such as employment, income, access to resources, and majority/ minority status in all participating countries. Adults with low literacy skills across all participating industrialized nations are more likely to live in under-resourced areas, be members of minority population groups, and/or are living in poverty (OECD, 2013). Analyses noted strong links between literacy skills and participation in everyday life-including civic engagement and mundane actives related to access to information, family matters, finances, and health (Desjardins et al., 2005; OECD, 2013; Rudd, Kirsch, & Yamamoto, 2004; Tuijnman, 1996). Furthermore, in all industrialized nations, older adults scored at lower proficiency levels than did younger working adults.

U.S. and international findings from all three waves of adult literacy assessments consistently indicate a continuing relationship between age and performance. An in-depth analysis of literacy skills among older adults was conducted based on the initial U.S. National Adult Literacy Survey (NALS) and a report, Literacy of Older Adults in America, was issued soon thereafter (Brown, Prisuta, Jacobs, & Campbell, 1996). This data reflected the performance of older adults living in households or in prisons (but not of those living in nursing homes) and is based on a sample 3,614 older adults: 2,267 adults aged 60-69 years, 1,005 adults aged 70-79 years, and 442 adults aged 80 years and older. Findings indicated that older adults demonstrate significantly lower and problematic proficiencies related to the use of prose materials (information presented in sentence and paragraph format), related to the use of document materials (such as schedules, forms, charts, or labels), and for quantitative tasks (such as adding up numbers or figuring a percentage). In the United States, almost three quarters of adults aged 60 years and older (71%) have limited prose literacy skills; more 80% have limited document skills, and 68% have limited quantitative skills. Furthermore, proficiencies in each of these areas decrease as age increases (Brown et al., 1996).

Even in countries with relatively high literacy skills such as Japan or the Netherlands, literacy skills of younger working populations are significantly higher than those of older adults. A 2016 analysis indicates that adults tend to lose their information-processing skills as they age, especially if they do not use them (OECD, 2016). In addition, older age may be associated with an established employment situation (not necessarily facing new challenges) or may reflect retirement status. An earlier Canadian based study on seniors noted that older adults have low literacy skills, in part, because of rapidly changing information and communication technologies (Statistics Canada, 1999).

Health Literacy

The foundation of health literacy is rooted in these national and international assessments of adult literacy skills begun in the 1990s. The 1992 publication and dissemination of survey findings drew the attention of researchers from the health field who were then determined to explore the possible links between literacy skills and health outcomes. First, however, early health literacy studies focused on measures of health literacy. Two early measures of health literacy designed to be used for clinical research, the REALM (Davis et al., 1993) and the TOFHLA (Parker, Baker, Williams, & Nurss, 1995) were modeled on component parts of general literacy assessments and used health words and materials. These tools allowed health researchers to differentiate between study participants with strong or weak "health literacy skills." Among the earliest studies were those of Baker and colleagues, who used the newly developed health literacy assessment tool, TOFHLA, to examine health literacy

among older adults. Baker and colleagues noted that health literacy declined with age (Baker, Gazmararian, Sudano, & Patterson, 2000), offering substantive proof of a previously undocumented issue. Subsequent studies focused on links between health literacy and various health outcomes.

In addition, three population-based measures of health literacy were developed to offer insight into health literacy across and within nations. The first such measure is the Health Activities Literacy Scale (HALS) which was based on 191–236 health items taken from the first two waves of adult literacy surveys (Rudd et al., 2004). The second measure was developed in preparation for the second U.S. National Assessment of Adult Literacy in 2003 and included 28 specific health-related items, added to the U.S. National Assessment of Adult Literacy survey (Kutner, Greenburg, Jin, & Paulsen, 2006). Researchers in Europe developed The European Union Health Literacy Questionnaire, which focused on perceived issues and experiences and was implemented in eight countries (HLS-EU Consortium, 2012; Sorensen et al., 2013).

Health literacy research efforts also focused on the suitability of health materials in light of what was known about population literacy skills. Over time, a vast literature accumulated about the quality of health information. Researchers, across numerous health specialties, examined the reading level of health materials and the match between the literacy demands of health information and the skills of the intended audiences. More recent studies looked beyond readability measures to examine qualities of written and posted texts as well as talk related to vocabulary, organization, as well as to the presentation of data and numeric concepts.

Health Literacy Research Findings

Health literacy researchers initially focused on appointment keeping, knowledge related to illness or medication, as well as on self-reports of behaviors for health promotion, disease prevention, and screening. Baker and colleagues focused several studies on Medicare managed care enrollees and found that elderly patients have limited ability to read and comprehend medical information pertinent to their health (Gazmararian et al., 1999). A follow-up study by the same team found that elders with limited literacy participate in fewer preventive care activities (Scott, Gazmararian, Williams, & Baker, 2002). In addition, inadequate literacy was found to be an independent risk factor for hospital admission among the elderly patients (Baker et al., 2002). Over time, more studies focused on the management of a chronic disease with specific measures such as A1C to compare and contrast outcomes for those with strong and those with low literacy skills. Overall, study findings indicated that people with strong literacy skills were more likely than those with limited literacy skills to engage in more health promoting and disease prevention activities such as the use of sunscreen or participation in screening The various population measures offered a clear indication of continued problems. Large proportions of adults have difficulty using everyday materials to accomplish mundane task, including those related to health. Analyses of each of the three measures of population health literacy indicated limited health literacy among significant proportions of the population in many industrialized nations. Furthermore, these studies consistently found even lower proficiency scores among older adults as well as among marginalized population groups such as those living in poverty, residing in rural or under- resourced areas, or members of minority or immigrant population groups.

Furthermore, health literacy studies indicate that health information, across multiple health disciplines, is neither well written nor well matched to the documented literacy skills of the public (Rudd, Rosenfeld, & Simmons, 2012). Currently, over 3,000 studies have found that the reading level of health education materials assessed far exceeds the documented reading skills of the public for whom they were developed (Rudd, 2013; Rudd, Anderson, Oppenheimer, & Nath, 2007). Examinations of cancer information similarly indicate that cancer information does not meet population literacy needs (Basch et al., 2018; Hoppe, 2010; Neuhauser, 2008; Pruthi et al., 2015; Rosenberg et al., 2016). For example, a recent review of patient guidelines for the management of the most common cancer diagnoses found that most of the information posted by the National Comprehensive Cancer Network (NCCN) had high demand scores for readability and complexity. The average reading grade level was above 10th grade, higher than the recommended 6th to 8th grade level; the charts and graphs were scored at moderate complexity level; and the score based on the CDC Health Literacy Index assessment tool was below the recommended rating for an appropriate health literacy demand (Tran et al., 2018).

Unfortunately, health literacy studies focused on links between health literacy and health outcomes were not merged with those studies focused on the quality of health information. Thus, we do not know, with certainty, whether the literacy skills of the patient or the mismatch between limited skills and inaccessible health information contributed the most towards generating negative health outcomes among those with limited literacy skills.

New Developments and Insights for Action

Health literacy, like overall literacy, is considered malleable and the idea that improvements in health literacy could lead to improvements in health outcomes was of great interest to practitioners and policy makers (IOM, 2004). However, there was an inherent dilemma for health practitioners. After all, their expertise and focus are on health and they have neither the skills nor the opportunities to improve the literacy skills of a population in need. Certainly, support for educational efforts was considered important. Yet, given the established link to health outcomes, waiting for improvements in the education sector would not be considered feasible. The dilemma for health practitioners and communicators was somewhat resolved through a deeper understanding of literacy. Subsequently, the concept of health literacy expanded beyond a focus on the skills of individuals.

With the recognition that literacy is based on interactions (between the reader and the text or between the listener and speaker, for example) and that both sides of the interaction must be addressed, opportunities for efficacious action on the part of the health sector were more clearly identified. The health sector could improve access to information by lowering the demand of health materials and improving the communication skills of health professionals. An additional consideration was added through the understanding that the application of health literacy and health communication skills are shaped, in part, by the context within which interactions take place. For example, a stressful environment influences one's ability to listen. In addition, time constraints on practitioners influence their ability to convey more in-depth information to their patients. Overall, the physical, social, and normative environment of health care settings can inhibit or facilitate the application of existing literacy/health literacy skills as well as the practice of efficacious communication efforts.

Consequently, a health literacy lens now offers a focus on the literacy skills and ability of members of the lay public as well as on the communication skills of health professionals; on the reading skills of the public as well as on the quality of health texts; on the communication skills of professionals as well as on the norms of health and health care practices; and on the navigation skills of the public as well as on the facilitating factors and hindrances found in health and health care institutions and systems. The premise of a broader health literacy construct is that changes in texts, in communication practices, as well as in the characteristics of health institutions and systems could improve health literacy and thereby influence health outcomes (IOM, 2004; Rudd, McCray, & Nutbeam, 2012). Thus far, several studies and program evaluations do indicate that improvements such as more accessible health information and enhanced communication strategies do improve health outcomes (Berkman et al., 2011; DeWalt et al., 2004; IOM, 2004; National Academy of Medicine, 2017).

Lessons for Cancer Prevention Efforts for Older Adults

Chesser and colleagues conducted a systematic review of the published literature exploring health literacy and older adults and, having found few studies, highlighted the importance of working to improve health care strategies for older adults with low health literacy (Chesser, Keene Woods, Smothers, & Rogers, 2016). A paucity of studies in this area is indicative of neglected needs.

Of course, many health topics are relevant for primary cancer prevention and cancer risk reduction. These more general topics, such as smoking cessation, physical activity, weight reduction, and participation in screening have been explored in relation to health literacy (Gebiersm de Winter, Luten, Jansen, & Reijneveld, 2014; Geboers, Winter, Luten, Jansen & Reijneveld, 2014; Oldach & Katz, 2014; Stewart et al., 2013; Zoeliner et al., 2016). Links have been established between a wide variety of disease prevention activities and health literacy. Overall, those with lower health literacy levels are less likely to engage in preventive behaviors than are those with higher literacy and health literacy skills (Berkman et al., 2011; DeWalt et al. 2004). Studies also indicate that those with lower numeracy skills face impediments. For example, Wood and colleagues examined the role of numeracy and risk of financial exploitation-raising the question of numeracy and health risks (Wood, Liu, Hanoch, & Estevez-Cores, 2016).

Cancer prevention programs developed for older adults face both common and unique challenges. Social scientists note that *cancer*, long used as a negative metaphor, still holds a sway over the fears of many. Literacy experts point out that abstract concepts are problematic for those with limited literacy skills. In this light, *prevention* is a difficult concept for people with limited literacy skills because of its abstract nature. More concrete concepts such as treatment resonate with greater ease (Kirsch, 2001). Furthermore, the documented mismatch between most health information, whether on the internet, in print, or delivered by voice serves to limit access to information and could, ultimately, inhibit informed action. The consensus among health literacy researchers and practitioners is that the development of messages and the design and implementation of a variety of disease prevention programs and materials can be improved through attention to literacy and can thereby contribute to action and improved outcomes. For example, Simmons and colleagues indicate that cancer prevention efforts that include attention to health literacy can successfully reduce communication barriers between consumers and providers and lead to sustainable health system policy changes (Simmons et al., 2017).

Attention to Rigorous Message Development

Cancer prevention efforts can be enhanced through adherence to rigorous formative research. Among the early pioneers in this effort was the National Cancer Institute (NCI) with its focus on improving health communication programs. NCI convened a health literacy committee in the mid-1990s bringing together early health literacy researchers and practitioners to expand insights for efficacious health communication in cancer related information for the public. The famous "pink book," *Making Health Communication Programs Work* highlighted the

importance of rigorous materials development, pilot testing, and attention to readability (Arkin, 1989). Health literacy efforts continue to highlight the need for rigor in health materials development and the importance of critical assessment processes.

Predating health literacy analyses, health communication specialists had long stressed the importance of rigorous formative research for shaping any health communication or health program design and for the development of materials intended for the public. Health education, health promotion, and health communication literatures consistently stress the importance of formative evaluation processes and piloting with members of the intended audience. For example, developed in the 1970s and revised several times thereafter, Pretesting in Health Communications sets out the argument for the value of pilot testing as well a step by step protocol for easy adherence (USDHHS, 1980). Both the 1985 and 1996 editions of Teaching Patients with Low Literacy Skills offered guidelines for the development, design, pilot testing, revision, and assessment of health materials (Doak, Doak, & Root, 1996). Unfortunately, lessons learned and the well-articulated need for rigor have not vet been uniformly put into action.

Attention to Vocabulary and Organization

Words are important. Readability assessments do highlight the difficulty of long words in English for those with compromised reading skills. Longer words in English are more likely to contain silent letters and are difficult to pronounce. However, short words such as risk, range, or normal reflect complex concepts that are not easily grasped and that are not considered by readability assessment tools. Consequently, clear communication guidelines indicate that jargon is to be avoided as is the use of rare words from medicine or science without explanations. Lessons drawn from literacy studies point to the importance of focusing on concrete words, providing definitions and examples, and offering specific steps with how-to components for cancer prevention measures. Health literacy assessment tools such as the CDC Index and the AHRQ PEMAT noted above both offer positive scores for messages that include concrete action steps.

Health literacy guidebooks and studies highlight the importance of rigorously following tested protocols for organization and design. Guidebooks, such as the classic text *Teaching Patients with Low Literacy Skills* (Doak et al., 1996) and the more recent USDHHS Toolkit (McGee, 2010) recommend the use of "chunking," placing like information together, and the use of organizational cues such as headings. The uncluttered design of a written or posted message, attention to font, provision of adequate white space, placement of visuals to avoid distraction all facilitate reading ease. For example, an early study conducted by the National Literacy and Health Program and the Canadian Public Health Association found that older adults have a

hard time finding the beginning of each line. They dislike forms with large amounts of text and forms that provide too little space for their responses. They found it difficult to find critical information when it is not highlighted in some way or follow instructions in materials when they are not written in the same order in which they are supposed to be carried out. Small design consideration can be problematic as well: older adults have a hard time reading light type on a dark background or differentiating colors in the greenblue–violet spectrum (Canadian Public Health Association, 1998).

Published assessments of health materials across a wide variety of topics do not yet indicate that developers have adhered to the recommended vocabulary, organization, and design elements of health texts that support reading ease and use. The applauded passage of the Plain Writing Act of 2010 (Public Law 11–274) has not guaranteed that clear and simple communication informs the development of health materials. Furthermore, the application of insights from assessment tools such as the *PMOSE/IKIRSCH* document assessment tool (Mosenthal & Kirsch, 1998), the *CDC Health Literacy Index* (Baur & Prue, 2014) or the AHRQ *PEMAT* (Shoemaker, Wolf, & Branch, 2014) have not yet been widely noted in the literature nor are their scores required by institutional review boards.

Attention to Numeracy

The adult literacy surveys found that numeracy skills in the United States are low in general and lower still among older adults. Thus, recent health literacy work suggests that numbers and numeric concepts, important components of prevention discussions, be used carefully, be accompanied by explanations, and follow tested guidelines in displays. This is, of course, of particular concern for those shaping cancer prevention messages where the term *risk* often abounds. Health communications include expectations that people will make use of arithmetic and draw meaning from percentages as well as from higher level tasks such as estimation, probability, problem-solving, and risk assessment—a key component of preventive messages. Such expectations are inappropriate in light of what is known about older adult's numeracy skills.

Public health and health care professionals are being encouraged to "do the math" for the reader or patient by simplifying numerical concepts (Apter et al., 2008). Data displays are often helpful but here too, attention to research findings should guide options for visuals. For example, Ancker found illustrations such as human figure icons to illustrate, compare, and contract data (Ancker, 2014) is most helpful. Tested suggestions also include providing numbers along with words (Peters et al., 2006), consistently using the same denominators in fractions (Ancker, 2006, 2014), and providing illustrations as well as explanations of range parameters and outliers (Zigmund-Fisher, 2014). The PMOSE/IKIRSCH noted above is a tool for assessing the "reading level" of displays lists, and charts is readily available but rarely used and cited.

Attention to Tasks

The task analyses undertaken for the adult literacy surveys considered what people had to do with the text and rated levels of complexity and difficulty. As we use texts, we are expected to locate information, match like information, compare or contrast details, read "between the lines" or interpret or link information to our particular needs or situation. Insights from the adult literacy rating schema can inform the development and design of cancer prevention messages as well. Those of us developing health information need to more carefully examine the materials themselves and then analyze the tasks people need to undertake to effectively use the materials (such as examine risk factors to determine where one fits or calculate nutritional factors in a meal) and shape materials to support these tasks. Furthermore, because cancer prevention efforts are concerned with health-promoting action, the more distal tasks require additional focus.

We differentiate here between proximal and distal tasks. Proximal tasks are those undertaken to use the text—such as reading directions, determining if the materials are directed to someone like you, or understanding a word or phrase. Distal tasks are those activities people are expected to engage in after using the materials or tools provided—such as developing plans to increase physical activity, exploring options for smoking cessation, testing strategies to reduce alcohol consumption or participating in early screening and detection opportunities. Thus, a key question that must be asked about the messages and information provided for cancer prevention is: *Does it help the individual take the needed and recommended action?*

An analysis of texts and tasks offer a more in-depth examination of materials than is currently undertaken by many professionals developing health materials and messages (Rudd, 2016). An understanding of text complexity and an analysis of tasks people are expected to undertake should be part of future health literacy and numeracy analyses to inform cancer prevention messages. This awareness also calls for a concrete "how-to" orientation for recommended action steps in cancer prevention messages.

Enhancing Professional Skills

Important health and disease prevention information is delivered through talk in the intimate clinician encounter and over the air waves. Across all media, literacy issues are similar. Nouri and Rudd conducted a literature review to assess the degree to which health literacy was explored in studies of the oral exchange in the clinical encounter and found that the literature was sparce (Nori & Rudd, 2015). Patient/provider communication studies have long been attentive to question asking, turn taking, and timing and have been including attention to vocabulary as well in the current decade (Roter, 2011). Unfortunately, a 2013 study indicated that physicians do not routinely apply the communication techniques recommended for use with patients who have low or limited literacy (Howard, Jacobson, & Kripalani, 2013)—such as those found in the Doak, Doak, and Root classic text referenced earlier (Doak et al., 1996). At the same time, the burden of responsibility does not lie with the patient or clinician. Systemic issues including the policies and practices in institutions can support or impede clinicians' ability to meet the literacy related needs of U.S. adults coming in for consultation or care (Brach et al., 2012).

Institutional Change

The call for action embedded in health materials and health messages most often sends people to public health and health care programs and institutions. Health literacy researchers have drawn attention to the complexity of health institutions and the sophisticated skills needed to access and navigate health and health care services and institutions (Dewalt et al., 2010; Rudd, Rezulli, Perreira, & Daltroy, 2004). Current developments in health literacy studies are bringing attention to systemic issues—the very capacity of health professionals and institutions to provide access to information and to support and sustain the active engagement of the public (Branch et al., 2012; Rudd, McCray, & Nutbeam, 2012).

Institutional norms, practices, and polices set guidelines and/or limits on professionals' time. However, time constraints particularly influence older adults' ability to fully engage in tasks such as filling out forms and engaging in dialogue and discussion (Sparks & Nausbaum, 2008). A growing number of institutions are undertaking an examination of entry forms, directives, and instructions—those elements of clinical encounters that are the responsibility of organizations and not of individual practitioners. Navigation studies are focusing on institutional norms as well as on policies and practices (Canadian Public Health Association, 1998; Horowitz et al., 2014; Oelschlegel, Grabeel, Tester, Heidel, & Russomanno, 2018). Continued efforts to identify and remove literacy related barriers to information, to care, and to services are needed.

Conclusions

Health literacy studies emphasize the importance of eliminating unnecessary barriers to the comprehension and use of health information. Doing so supports respectful interactions and promotes the use of information for carrying out health tasks as well as for making health-related decisions for cancer prevention engagement. Health literacy insights noted above are useful for shaping cancer prevention initiatives for elders by lessening the effects of welldocumented literacy and numeracy deficits among older adults in our society to help everyone more skillfully access and use information for mundane and critical decisions.

There is growing consensus that those who provide health information for the public, whether written, spoken, posted on line or on walls, illustrated in diagrams and charts, or sent via e-mail or mobile phone have a responsibility to become familiar with literacy issues and the literacy skills of the public. As is noted above, guidebooks and protocols are readily available and newly developed tools help researchers and practitioners both examine the "accessibility" of existing health materials' and help shape new information for the public. Study findings and the fact that these resources are not yet uniformly used are bringing increased attention to the need for rigorous formative research. Policy considerations must weigh the value of articulated protocols for contracts and reviews and, perhaps, consider the need for regulations related to the production of health materials and health messages for the public.

As is noted in the introduction above, the 2011 National Prevention Strategy and the subsequent, The State of Ageing and Health in America (Centers for Disease Control and Prevention, 2013) both highlight the importance building knowledge, the importance of available health information, and the critical role of health communication. Both reports recommend attention to health literacy findings so that information is more accessible to the public. Efforts to communicate with older adults about key issues related to cancer prevention must be particularly attentive to literacy related issues because of the well-documented problems older adults face with literacy and numeracy. Cancer prevention information can be made more readily available as well as more accessible and usable.

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Conflict of Interest

The author reports no conflict of interest.

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References

- Amalraj, S., Starkweather, C., Nguyen, C., & Naeim, A. (2009). Health literacy, communication, and treatment decision-making in older cancer patients. Oncology (Williston Park, N.Y.), 23, 369–375.
- Ancker, J. S. (2014). Issues and challenges in the era of shared decision making: Explaining risk and uncertainty in IOM (Institute of Medicine) Health Literacy and Numeracy: Workshop Summary. Washington, DC: The National Academies Press.
- Ancker, J. S., Senathirajah, Y., Kukafka, R., & Starren, J. B. (2006). Design features of graphs in health risk communication: A systematic review. *Journal of the American Medical Informatics Association*, 13, 608–618. doi:10.1197/jamia.M2115
- Apter, A. J., Paasche-Orlow, M. K., Remillard, J. T., Bennett, I. M., Ben-Joseph, E. P., Batista, R. M.,...Rudd, R. E. (2008). Numeracy and communication with patients: They are counting on us. *Journal of General Internal Medicine*, 23, 2117–2124. doi:10.1007/s11606-008-0803-x
- Arkin, E. B. (1989). Making health communication programs work. NIH Report NIH-89–1493. Bethesda, MD: National Cancer Institute.
- Baker, D. W., Gazmararian, J. A., Sudano, J., & Patterson, M. (2000). The association between age and health literacy among elderly persons. *The Journals of Gerontology*: B, 55, S368–S374. doi: 10.1093/geronb/55.6.S368
- Baker, D. W., Gazmararian, J. A., Williams, M. V., Scott, T., Parker, R. M., Green, D.,...Peel, J. (2002). Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*, 92, 1278–1283. doi: 10.2105/AJPH.92.8.1278
- Basch, C. H., Ethan, D., MacLean, S. A., Fera, J., Garcia, P., & Basch, C. E. (2018). Readability of prostate cancer information online: A cross-sectional study. *American Journal of Men's Health*, **12**, 1665–1669. doi:10.1177/1557988318780864
- Baur, C., & Prue, C. (2014). The CDC Clear Communication Index is a new evidence-based tool to prepare and review health information. *Health Promotion Practice*, 15, 629–637. doi:10.1177/1524839914538969
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine*, 155, 97–107. doi:10.7326/0003-4819-155-2-201107190-00005
- Branch, C., Dreyer, B., Schyve, P., Hernandez, L. M., Baur, C., Lemerise, A. J., & Parker, R. (2012). Attributes of a health literate organization. Discussion Paper. IOM Roundtable on Health Literacy. National Academies of Science. Washington, DC: The National Academies Press.
- Brown, H., Prisuta, R., Jacobs, B., & Campbell, A. (1996). Literacy of older adults in America: Results from the national adult literacy survey, NCES 97–576. Washington, DC: U.S. Department of Education. National Center for Education Statistics.
- Canadian Public Health Association. (1998). Creating plain language forms for seniors: A guide for the public, private, and not-for-profit sectors. Ottawa, Canada: Canadian Public Health Association.
- Centers for Disease Control and Prevention. (2013). *The State of Aging and Health in America 2013*. Atlanta, GA: Centers for Disease Control and Prevention, US Dept of Health and Human Services.

- Chesser, A. K., Keene Woods, N., Smothers, K., & Rogers, N. (2016). Health literacy and older adults: A systematic review. *Gerontology & Geriatric Medicine*, 2, 2333721416630492. doi:10.1177/2333721416630492
- Davis, T. C., Long, S. W., Jackson, R. H., Mayeaux, E. J., George, R. B., Murphy, P. W., & Crouch, M. A. (1993). Rapid estimate of adult literacy in medicine: A shortened screening instrument. *Family Medicine*, 25, 391–395.
- Desjardins, R., Murray, T. S., & Tuijnman, A C. (2005). Learning a living: First results of the Adult Literacy and Life Skills survey. Ottawa Canada: Statistics Canada.
- Dewalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes: A systematic review of the literature. *Journal of General Internal Medicine*, 19, 1228–1239. doi:10.1111/j.1525-1497.2004.40153.x
- DeWalt, D. A., Callahan, L. F., Hawk, V., Broucksou, K. A., Hink, A., Rudd, R. E., & Brach, C. (2010). *Health literacy universal* precautions Toolkit. North Carolina Network Consortium and the Cecil G. Sheps Center for Health Services Research. Chapel Hill, NC: University of North Carolina at Chapel Hill.
- Doak, C. C., Doak, L. G., & Root, J. H. (1996). Teaching patients with low literacy skills. 2nd ed. Philadelphia: J.B. Lippincott Co. Out of print. Retrieved April 22, 2019, from https://www.hsph. harvard.edu/healthliteracy/assessing-and-developing-materials.
- Gazmararian, J. A., Baker, D. W., Williams, M. V., Parker, R. M., Scott, T. L., Green, D. C.,...Koplan, J. P. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA*, 281, 545–551. doi:10.1001/jama.281.6.545
- Geboers, B., de Winter, A. F., Luten, K. A., Jansen, C. J., & Reijneveld, S. A. (2014). The association of health literacy with physical activity and nutritional behavior in older adults, and its social cognitive mediators. *Journal of Health Communication* 19(Suppl 2): 61–76. doi:10.1080/10810730.2014.934933
- HLS-EU Consortium. (2012). Comparative report of health literacy in eight EU member states. The European Health Literacy Survey HLS-EU.
- Hoppe, I. C. (2010). Readability of patient information regarding breast cancer prevention from the Web site of the National Cancer Institute. *Journal of Cancer Education*, 25, 490–492. doi:10.1007/s13187-010-0101-2
- Horowitz, A. M., Maybury, C., Kleinman, D. V., Radice, S. D., Wang, M. Q., Child, W., & Rudd, R. E. (2014). Health literacy environmental scans of community-based dental clinics in Maryland. *American Journal of Public Health*, **104**, e85–e93. doi:10.2105/AJPH.2014.302036
- Howard, T., Jacobson, K. L., & Kripalani, S. (2013). Doctor talk: Physicians' use of clear verbal communication. *Journal of Health Communication*, 18, 991–1001. doi:10.1080/10810730.2012.7 57398
- Institute of Medicine (IOM). (2004). *Health literacy: A prescription to end confusion. committee on health literacy*. Washington, DC: National Academies Press.
- Institute of Medicine (IOM). (2013). *Health literacy: Improving health, health systems, and health policy around the world: Workshop summary. Health Literacy Roundtable.* Washington, DC: The National Academies Press.
- Kirsch, I. S. (1993). Adult Literacy in America: A first look at the results of the national adult literacy survey. Washington, DC:

US Government Printing Office, Superintendent of Documents, 20402 (Stock No. 065-000-00588-3).

- Kirsch, I. S. (2001). The international adult literacy survey (IALS): Understanding what was measured. *ETS Research Report Series*, 2001, i–61. doi:10.1002/j.2333–8504.2001.tb01867.x
- Koh, H. K., & Rudd, R. E. (2015). The arc of health literacy. JAMA, 314, 1225–1226. doi:10.1001/jama.2015.9978
- Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy. NCES 2006–483. Jessup, MD: ED Pub.
- McGee, J. (2010). Toolkit for making written materials clear and effective. Centers for Medicare and Medicaid Services. Washington, DC: USDHHS. Retrieved April 22, 2019, from https://www.cms.gov/Outreach-and-education/Outreach/ WrittenMaterialsToolkit?index.html.
- Mosenthal, P., & I. Kirsch (1998). A new measure for assessing document complexity: The PMOSE/IKirsch document readability formula. *Journal of Adolescent and Adult Literacy*, 41, 638–657.
- Murray, T. S., Kirsch, I. S., & Jenkins, L. B. (1997). Adult literacy in OECD countries: Technical report on the international adult literacy survey. Washington, DC: US Department of Education.
- National Prevention Council. (2011). *National Prevention Strategy*. Washington, DC: U.S. Department of Health and Human Services, Office of the Surgeon General.
- National Academy of Medicine. (2017). Community based health literacy interventions. health literacy roundtable. National Academies of Science. Washington, DC: National Academies Press.
- Neuhauser, L., & Kreps, G. L. (2008). Online cancer communication: meeting the literacy, cultural and linguistic needs of diverse audiences. *Patient Education and Counseling*, 71, 365–377. doi:10.1016/j.pec.2008.02.015
- Nouri, S. and Rudd, R. E. (2015). Health literacy in the 'oral exchange": An important element of patient-provider communication. *Journal of Patient Education and Counseling*, 98, 565–571. doi:10.1016/j.pec.2014.12.002
- OECD. (2013). OECD skills outlook 2013: first results from the survey of adult skills. Paris: OECD Publishing.
- OECD. (2016). Skills in focus #3. Paris: OECD Publishing.
- Oelschlegel, S., Grabeel, K. L., Tester, E., Heidel, R. E., & Russomanno, J. (2018). Librarians promoting changes in the health care delivery system through systematic assessment. *Medical Reference Services Quarterly*, 37, 142–152. doi:10.10 80/02763869.2018.1439216
- Oldach, B. R. & Katz, M. L. (2014). Health literacy and cancer screening: a systematic review. *Patient Education and Counseling*, 94, 149–157. doi:10.1016/j/pec.2013.10.001. Epub 2013 Oct 14
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10, 537–541. doi:10.1007/BF02640361
- Peters, E., Västfjäll, D., Slovic, P., Mertz, C. K., Mazzocco, K., & Dickert, S. (2006). Numeracy and decision making. *Psychological Science*, 17, 407–413. doi:10.1111/j.1467-9280.2006.01720.x
- Pruthi, A., Nielsen, M. E., Raynor, M. C., Woods, M. E., Wallen, E. M., & Smith, A. B. (2015). Readability of American online patient education materials in urologic oncology: A need

- Public Law 11–274. The Plain Writing Act of 2010. Retrieved April 22, 2019, from http://www.gpo.gov/fdsys/pkg/PLAW-111publ274/pdf/PLAW-111publ274.pdf.
- Rosenberg, S. A., Francis, D., Hullett, C. R., Morris, Z. S., Fisher, M. M., Brower, J. V.,...Kimple, R. J. (2016). Readability of online patient educational resources found on NCI-Designated cancer center web sites. *Journal of the National Comprehensive Cancer Network*, 14, 735–740. doi:10.6004/jnccn.2016.0075
- Roter, D. L. (2011). Oral literacy demand of health care communication: Challenges and solutions. *Nursing Outlook*, 59, 79–84. doi:10.1016/j.outlook.2010.11.005
- Rudd, R. E. (2007). Health literacy skills of US adults. American Journal of Health Behavior, 31(Supplement 1), S8–S18. doi:10.5993/AJHB.31.s1.3
- Rudd, R. E. (2013). Needed action in health literacy. *Journal of Health Psychology*, **18**, 1004–1010. doi:10.1177/1359105312470128
- Rudd, R. E. (2016). Numbers get in the way. Washington, DC: Commentary, National Academy of Medicine. doi:10.31478/201605e
- Rudd, R. E., Anderson, J. E., Oppenheimer, S. & Nath, C. (2007). Health Literacy: An update of public health and medical literature, chapter 6 in Comings. In J. P., B. Garner, & C. Smith (Eds.), *Review of adult learning and literacy* (pp. 175–204, volume 7). Mahway, NJ: Lawrence Erlbaum Associates.
- Rudd, R. E., Kirsch, I., & Yamamoto, K. (2004). Literacy and health in America. Policy Information Report. Princeton NJ: Educational Testing Service.
- Rudd, R. E., McCray, A. & Nutbeam, D. (2012). Heath literacy and definitions of terms. Chapter 2 in Health literacy in context: international perspectives. Hauppauge: Nova Science Publishers. pp. 13–32.
- Rudd, R. E., Rezulli, D., Perreira, A., & Daltroy, L. D. (2004). The patient's health experience, chapter 5. In J. G. Schwartzberg, J. B. VanGeest, C. C. Want, J. A. Gazmararian, R. M. Parker, D. L. Roter, R. E. Rudd, D. Schillinger (Eds.). Understanding health literacy: Implications for medicine and public health. Chicago, IL: AMA Press.
- Rudd, R. E., Rosenfeld, L., & Simonds, V. W. (2012). Health Literacy: A new field of research with links to communication. *Atlantic Journal of Communication*, 20: 16–30. doi:10.1080/15 456870.2012.637025
- Scott, T. L., Gazmararian, J. A., Williams, M. V., & Baker, D. W. (2002). Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*, 40, 395–404.
- Shoemaker, S. J., Wolf, M. S., & Brach, C. (2014). Development of the Patient Education Materials Assessment Tool (PEMAT): A new measure of understandability and actionability for print and audiovisual patient information. *Patient Education and Counseling*, 96, 395–403. doi:10.1016/j.pec.2014. 05.027
- Simmons, R. A., Cosgrove, S. C., Romney, M. C., Plumb, J. D., Brawer, R. O., Gonzalez, E. T.,...Moore, B. S. (2017). Health Literacy: Cancer prevention strategies for early adults. *American Journal of Preventive Medicine*, 53, S73–S77. doi:10.1016/j. amepre.2017.03.016

- Sorensen, K., Pelikan, J. M., Rothlin, F., Ganahl, K., Slonska, Z., Doyle, G., Fullam, J., ..., Brand, H. (2015). Health Literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *European Journal of Public Health*, 25, 1053–1058. doi:10.1093/eurpub/ckv043
- Sparks, L. & J. F. Nausbaum (2008). Health literacy and cancer communication with older adults. *Patient Education and Counseling*, 71, 345–350. doi:10.1016/j.pec.2008.02.007
- Statistics Canada. (1999). Canada's seniors. division of aging and seniors. Ottawa, ON: Statistics Canada.
- Stewart, D. W., Adams, C. E., Cano, M. A., Correa-Fernández, V., Li, Y., Waters, A. J.,...Vidrine, J. I. (2013). Associations between health literacy and established predictors of smoking cessation. *American Journal of Public Health*, **103**, e43–e49. doi:10.2105/ AJPH.2012.301062
- Tran, B. N. N., Ruan, Q. Z., Epstein, S., Ricci, J. A., Rudd, R. E., & Lee, B. T. (2018). Literacy analysis of National Comprehensive Cancer Network patient guidelines for the most common malignancies in the United States. *Cancer*, 124, 769–774. doi:10.1002/cncr.31113
- Tuijnman, A. (1996). The International Adult Literacy Survey (IALS). Results and highlights from an international perspective:

IALS in relation to economies and labour markets. A workshop on 'Literacy, Economy and Society', Calgary, Canada. Retrieved April 22, 2019, from http://www.publications.gc.ca/ site/eng/289486/publication.html.

- USDHHS (1980). Pretesting in health communications: methods, examples, and resources for improving health messages and materials. Revised. Washington DC: Department of Health and Human Services. Retrieved April 22, 2019, from https://eric. ed.gov/?idED204438.
- Wood, S. A., Liu, P. J., Hanoch, Y., & Estevez-Cores, S. (2016). Importance of numeracy as a risk factor for elder financial exploitation in a community sample. *The Journals of Gerontology*, *Series B: Psychological Sciences and Social Sciences*, 71, 978– 986. doi:10.1093/geronb/gbv041
- Zigmund-Fisher, B. J. (2014). Communicating quantitative decision making. In Health literacy and numeracy: Workshop summary Washington, DC: The National Academies Press.
- Zoellner, J., You, W., Almeida, F., Blackman, K. C., Harden, S., Glasgow, R. E.,...Estabrooks, P. A. (2016). The influence of health literacy on reach, retention, and success in a worksite weight loss program. *American Journal of Health Promotion: AJHP*, **30**, 279–282. doi:10.1177/0890117116639558