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Robert Simmons

Thomas Jefferson University

Susan C. Cosgrove

Health Care Improvement Foundation

Martha C. Romney

Thomas Jefferson University


James D. Plumb

Thomas Jefferson University

Rickie O. Brawer

Thomas Jefferson University

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Authors

Robert Simmons, Susan C. Cosgrove, Martha C. Romney, James D. Plumb, Rickie O. Brawer, Evelyn T. Gonzalez, Linda G. Fleisher, and Bradley S Moore

Health Literacy: Cancer Prevention Strategies for Early Adults

Robert A. Simmons, DrPH, MPH, MCHES, CPH,¹ Susan C. Cosgrove, MPA, CPHQ,² Martha C. Romney, RN, MS, JD, MPH,¹ James D. Plumb, MD, MPH,³ Rickie O. Brawer, PhD, MPH, MCHES,⁴ Evelyn T. Gonzalez, MA,⁵ Linda G. Fleisher, PhD,⁵ Bradley S. Moore, MPH²

From the ¹College of Population Health, Thomas Jefferson University, Philadelphia, Pennsylvania; ²Health Care Improvement Foundation, Philadelphia, Pennsylvania; ³Thomas Jefferson University Center for Urban Health, Philadelphia, Pennsylvania; ⁴Thomas Jefferson University Hospital, Philadelphia, Pennsylvania; and ⁵Fox Chase Cancer Center, Philadelphia, Pennsylvania

Address correspondence to: Robert A. Simmons, DrPH, MPH, MCHES, CPH, Associate Professor, MPH Program Director, Jefferson College of Population Health, 901 Walnut St., 10th Floor, Philadelphia PA 19107. E-mail: robert.simmons@jefferson.edu.

Health literacy, the degree to which individuals have the capacity to obtain, process, and understand health information and services needed to make health decisions, is an essential element for early adults (aged 18–44 years) to make informed decisions about cancer. Low health literacy is one of the social determinants of health associated with cancer-related disparities. Over the past several years, a nonprofit organization, a university, and a cancer center in a major urban environment have developed and implemented health literacy programs within healthcare systems and in the community. Health system personnel received extensive health literacy training to reduce medical jargon and improve their patient education using plain language easy-to-understand written materials and teach-back, and also designed plain language written materials including visuals to provide more culturally and linguistically appropriate health education and enhance web-based information. Several sustainable health system policy changes occurred over time. At the community level, organizational assessments and peer leader training on health literacy have occurred to reduce communication barriers between consumers and providers. Some of these programs have been cancer specific, including consumer education in such areas as cervical cancer, skin cancer, and breast cancer that are targeted to early adults across the cancer spectrum from prevention to treatment to survivorship. An example of consumer-driven health education that was tested for health literacy using a comic book–style photonovel on breast cancer with an intergenerational family approach for Chinese Americans is provided. Key lessons learned from the health literacy initiatives and overall conclusions of the health literacy initiatives are also summarized.

INTRODUCTION

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.¹ Numerous studies have demonstrated that low health literacy is a contributing factor to poor health status and outcomes, higher premature mortality rates, lack of adherence to medical recommendations, and higher direct and indirect health costs.^{2,3} The importance of health literacy is highlighted in a number of national plans and guidelines, *Healthy People 2020*,⁴ the National Academy of Medicine's Ten Attributes of a Health Literate Health Care Organization,⁵ The Guide to Community Preventive Services,⁶ recommendations from the U.S. Preventive Services Task Force,⁷ and the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care.⁸ These guidelines, informed by the peer-reviewed literature, describe multiple interventions focused on improving consumer understanding to inform decision making about prevention, early screening, and treatment to improve health outcomes and quality of life, and to reduce costs across chronic diseases and different types of cancer.^{2,3,9-14} This article, focusing on early adults (aged 18–44 years), addresses how evidence-based health literacy practices can improve patient education and system changes, and how community organizations can play a vital role in educating consumers about cancer prevention and engagement with healthcare providers.¹⁵

Recent studies have investigated the association of health literacy with cancer-related attitudes, knowledge, and behaviors to educate and increase patient trust, self-efficacy, and engagement in decision making.^{2,10-12} Systematic review of the literature on health literacy in early adults with and without chronic illnesses confirms the association of lower health literacy with poorer health

behaviors and adverse health outcomes, and highlights their use of technology and the Internet as primary information sources.

HEALTH LITERACY APPROACHES TO CANCER PREVENTION

Findings from many studies confirm that low health literacy is one of the social determinants of health associated with cancer-related disparities, and that expanding partnerships with community-based organizations and consumers address unmet needs associated with cancer disparities.^{3,11-13} In Southeastern Pennsylvania, several health systems joined in efforts to improve health literacy for all patients. Nine hospitals participate in the Southeastern Pennsylvania Regional Enhancements Addressing Disconnects (SEPA-READS), a regional collaborative developed in 2010 and coordinated by two Philadelphia-based organizations, the Health Care Improvement Foundation and Thomas Jefferson University and Hospitals. Also, the National Cancer Institute–designated Fox Chase Cancer Center (FCCC) initiative has addressed health literacy across the cancer continuum, providing cancer education training and materials for healthcare providers and consumers throughout the region.

The multifaceted SEPA-READS initiative incorporates various program components and strategies based on best practices in the fields of education, health care, and public health. Education and peer learning are key drivers meeting SEPA-READS' objectives: (1) to enhance the capacity of healthcare systems and health professionals to address health literacy needs; and (2) to improve the ability of consumers and patients to communicate with providers and staff to increase capacity to effectively act on health information. Training for healthcare professionals employs a “train the trainer” approach, to support internal staff education and sustained

organizational change. Originally intended to benefit older adults with cardiovascular disease, the health literacy efforts of SEPA-READS are now applied to all ages of adult patients and consumers.¹⁶

CREATING A CULTURE OF HEALTH LITERACY

Health literacy interventions have the potential to be easily adapted in other contexts or to a targeted audience. FCCC, located in Philadelphia, integrates organizational, community, and research strategies to address health literacy across the cancer spectrum from prevention, treatment, and survivorship.

At the organizational level, health and patient educators spearheaded an initiative to build awareness about health literacy. Activities included an organizational assessment, identifying and training health literacy “champions” throughout the organization, and a standing committee to review patient education resources and materials. A health literacy guide on informed consent and technical resources was developed for the broader community.^{17,18} Easy-to-read educational materials were developed on a broad range of cancer topics as FCCC developed and tested plain language text messages to address no-show rates on the mobile mammography unit and a text messaging intervention for low-income pregnant women smokers. Educational materials were developed at a sixth grade reading level.¹⁹ Outcomes included a health literacy champion core facility to facilitate plain language clinical trial information, review health literacy of patient-related information, and assist researchers to develop innovative behavioral interventions for those with limited literacy (e.g., text messaging). Standard operating procedures for health literacy review and guidelines were instituted in public and research communications.

Specific practices taught as part of the SEPA-READS curriculum and incorporated in FCCC's health literacy programs include using plain language, confirming understanding through teach-back, and creating easily-understood written and web-based materials. Implementing these practices are steps toward addressing communication barriers and promoting the prevention, screening, and treatment of cancer.

STRATEGIES TO ADDRESS CANCER COMMUNICATION

Early adults need access to information about cancer prevention and care that is easy to understand and linguistically appropriate. Screening for many cancers, including skin, cervical, and breast cancers, is critical for this age group. Providing clear and actionable health information supports prevention efforts. Healthcare provider training through SEPA-READS and FCCC encourages the use of the proven strategies described below with all age groups.

Participating health systems have taken a variety of approaches to incorporate these strategies into their organization.

Plain Language

Although all patients may struggle to understand medical jargon, medically underserved communities and patients who speak English as a second language are at greater risk. Using plain language means conveying information simply and clearly in common words that patients are able to understand. It is a recognized strategy for clearly communicating health information, both spoken and written, and addressing the health literacy needs of all patients. Even common

words, such as “positive” or “negative,” can be confusing to patients in the medical context. Examples of plain language word substitutions related to cancer care are provided in Table 1.

Teach-back

Studies show that 40%–80% of the medical information shared during office visits is forgotten immediately and nearly half of the retained information is incorrect.²⁰ The teach-back communication method is a way healthcare providers can confirm patient understanding by asking them to state in their own words what they need to know or do about their condition(s). Teach-back improves patient understanding and adherence, decreases call backs and cancelled appointments, and improves patient satisfaction and outcomes.²¹ One can say, “We covered a lot today and I want to make sure that I explained things clearly. Let’s review what we discussed. Please describe the three things you agreed to do to help you prevent and reduce the risk of cancer.”

Designing Health Education Materials

The design of health education materials that promote health literacy, including paper, web, and digital documents, brings together prose, graphics, and design elements including white space, font type/size, and structural typography. A plain language document is one in which people can find and understand what they need, and act appropriately. Key elements of plain language include using simple language and defining technical terms, using short sentences and active voice when possible, breaking complex information into understandable sections, placing the most important behavioral or action steps first, and providing ample white space so pages are easier to read.²²

Photonovels, comic book–style educational materials using photographs and conversation bubbles, are one example of providing context for the information in an easy-to-understand format.²³ In Philadelphia, culturally appropriate photonovels are used to address breast cancer prevention and early detection among African American, Chinese, and Vietnamese women. The photonovel excerpt (Appendix Figure 1) was based on focus groups held with women from each culture to assess their knowledge, attitudes/beliefs about breast cancer, and their concerns about breast exams and mammograms. An advisory group of women for each photonovel assisted with story development, cultural relevance and context, and ensured the information was easy to understand, actionable, and in the readers' preferred languages. An intergenerational family approach was preferred, as young women often care for their parents and grandparents as well as their own children.

Implementing Strategies to Improve Communication About Cancer

Plain language, teach-back, and designing written materials are core components of SEPA-READS training, and have been implemented in partner hospitals in multiple ways. These techniques are most effective when implemented together.

Intervention information is self-reported in semiannual activities evaluations. Multiple hospitals have patient and family education committees that review all materials to ensure they adhere to the principles of plain language communication. Teach-back training has been incorporated into staff educational activities including orientation, annual competencies, Grand Rounds, skills labs, refresher sessions, and elective courses. Teach-back has been designated as one health system's official form of communication. Some health systems document the use of teach-back in electronic medical records. Written materials have been revised based on feedback from the

target audiences, and other materials (DVDs, videos, demonstrations) are used in addition to written materials for patient education. Implementing multiple strategies within a health system results in progress toward becoming a health literate organization.

LESSONS LEARNED AND CONCLUSIONS

Lessons Learned

There have been many “lessons learned” over the years from the SEPA READS and FCC initiatives to improve health literacy.

Flexibility. Programs need to be flexible to meet specific healthcare and community organization needs. The preferred length and depth of the training programs varied by organization and adaptations were made to shorten training programs and develop online modules. Advanced health literacy training programs have been offered for organizations who wanted to go beyond the initial three training programs.

Importance of champions. Identifying and nurturing organizational champions within healthcare and community organizations is an essential component of sustained actions to improve health literacy. Although a health literacy initiative may have begun in one department such as in oncology or in cardiovascular health, champions needed to be developed across various departments in organizations.

Inclusion. In both initiatives, community members, patients, and healthcare professionals actively participated on advisory committees in the design, implementation, and evaluation of the

health literacy initiatives. Such engagement helped create a “sense of ownership” and sustain participation.

Systems focus. To sustain health literacy initiatives, a systems approach is needed. In the SEPA-READS grant-funded project, hospitals were provided an annual stipend and used their funds to support their health literacy action plan. Some hospitals chose to buy a percentage of time for a person on the Patient Education Committee to serve as the health literacy internal coordinator. Others chose to use the resources for enhancing their written materials, resources for oral communication, or to improve signage for patients (wayfinding).

Changing norms. The FCCC project used a multilevel inclusive approach to the establishment and maintenance of health literacy best practices, many of which led to standard operating policies and procedures. Increasingly, patient communication and education applications using health literacy principles were required in grant proposals.

Scaling up. The health literacy initiatives from both FCCC and SEPA-READS have been “scaled up” over the years. Both organizations have expanded their health literacy and cultural competency initiatives to more diverse populations, including organizations serving immigrants and refugees. SEPA-READS expanded beyond the five county southeast Philadelphia area and formed a statewide Pennsylvania Health Literacy Coalition with organizational partners throughout the Commonwealth.

CONCLUSIONS

The implementation of health literacy programs in the Philadelphia region included evidence-based practices for addressing unmet cancer communication needs for early adults. Multiple health systems applied health literacy principles to customize patient education materials to meet the target populations' needs.

The implications for future public health practice are significant. Engaging early adults in the development of health literate prevention and early detection communications can enhance understanding and supports the sharing of information with peer and family members including children, parents, and grandparents.^{24,25}

The links between health literacy and cancer prevention, screening, and treatment are evident; understanding how early adults process health information about cancer and other diseases could be enhanced by further research into effective communication and messaging for that age group. Improving patient-provider communication methods and using easy-to-understand printed and electronic materials can advance patient knowledge and understanding and lead to improved cancer screening, risk communication, and patient outcomes.²⁴⁻²⁶ Targeting health literacy education efforts in cancer prevention and addressing the specific communication needs of early adults can improve their own health and also promote health for multiple generations from youth to seniors.

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Table 1. Plain Language Examples in Cancer Education

| Medical term | Plain language substitute |
|---------------------|--|
| Carcinogen | Cancer-causing |
| Intravenous | Into your vein, into your blood stream |
| Mammogram | Breast health test |
| Pulmonary | Related to the lungs |
| Tumor | Growth, lump |
| Verify | Check, find out |

Source: CDC National Center for Health Marketing, Plain Language Thesaurus for Health Communication, 2007,

https://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf

Appendix Figure 1. “Regular Breast Examination Can Prolong Your Life”, a bilingual photonovel that depicts a discussion between a Chinese young adult and her mother and grandmother.

Thomas Jefferson University and Hospitals, Center for Urban Health

