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Cooperative Extension and Health Literacy: A National Focus

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Health literacy is often defined as the degree to which an individual has the capacity to obtain, communicate, process and understand basic health information and services to make appropriate health decisions. Research shows that 30 million Americans have Below Basic health literacy skills. People with low health literacy skills contribute to higher utilization of health care services. This equates to an excess of \$230 billion a year in health care costs linked to low literacy in the United States. The primary responsibility for improving health literacy lies with public health professionals and the health care and public health systems. However, studies find that interventions using principles of health literacy, applied in community-based settings, can result in improved outcomes at the population level. In this article, the Health Literacy Action Team members consider the role of Extension in this important area, and suggest practices in incorporating health literacy into existing Extension programs and educational materials, and future resources for Extension and community partners.

Keywords: Cooperative Extension, Extension, Extension programs, health, health care systems, health literacy, public health, Health and Wellness Framework, ECOP Action Teams

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Introduction

Given the national trends in health, the Extension Committee on Organization and Policy (ECOP) established a Health Task Force whose role was to review health priorities both internal and external to Cooperative Extension (Extension). The goal of the Task Force was to identify emerging needs and how Extension might best respond to these needs, and to create a new programmatic focus to positively influence the social, economic, and environmental determinants of health.

The research and work of the Task Force resulted in the Cooperative Extension's National Framework for Health and Wellness (Braun et al., 2014) that was adopted by ECOP. In an assessment of national trends, the Task Force identified five topic areas that are included in the Framework: chronic disease prevention and management, health in all policies, health insurance literacy, health literacy, and positive youth development for health. Upon adoption of the Framework, Action Teams in each of these five areas were formed. This article focuses on the activities of the Health Literacy Action Team, comprised of research and Extension professionals from across the nation.

Health Literacy

It is important to recognize that literacy and health literacy are not the same. Literacy is a person's ability to read and write. It is often referred to as basic or fundamental literacy as it helps individuals to participate fully in their community and wider society (Zarcadoolas, Pleasant, & Greer, 2006).

Individuals navigating the nation's health care system can be overwhelmed when they lack the necessary skills. "Health literacy" is the term used to include all the skills that, when used, enable individuals to act on information and live healthier lives (Centre for Literacy, 2011). Required skills include reading, writing, listening, speaking, numeracy, and critical analysis.

Typically, health literacy is used when referring to an individual's ability to understand information in print form. However, it is recognized that other forms of delivery may impact one's health literacy, such as communications provided verbally and visually or information delivered through the media and accessed electronically (U.S. Department of Health and Human Services [USHHS], 2006).

Health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of health information and care providers, including doctors, nurses, administrators, home health workers, the media, and many others (Centers for Disease Control and Prevention [CDC], 2016). Moreover, health literacy is influenced by an individual's cultural and social

background, as well as interactions with health systems (Johnson, 2013). All of these factors and others contribute to an individual's health outcomes and the associated costs.

A 2003 National Assessment of Adult Literacy (National Center for Education Statistics, 2006) reported on the health literacy of more than 19,000 adults (aged 16 and older) using a health literacy scale with four levels: Below Basic, Basic, Intermediate, and Proficient. In a self-assessment of overall health, adults in the "Below Basic" health literacy level reported their health as poor (42%) and reported a lack of health insurance (28%). By comparison, of those rated as "Proficient" on the health literacy level, 3% reported their health as poor and 7% reported a lack of health insurance. Additionally, tested adults receiving Medicare and Medicaid had "Below Basic" health literacy levels (27% and 30%, respectively). The national assessment found that "nearly nine out of ten adults may lack the skills needed to manage their health and prevent disease" (U.S. Department of Health and Human Services [USHHS], n.d.).

Populations most likely to experience low health literacy are older adults, racial and ethnic minorities, those with less than a high school degree or GED (General Equivalency Diploma), those with low income, non-native speakers of English, and people with compromised health status (USHHS, n.d.). Education, language, culture, access to resources, and age are also factors that affect an individual's health literacy skills.

Strategies and Process

In 2014, when the Action Teams were formed, Extension had no recognized formal role within the national health care model, although Extension had provided health-related programs and information for more than a century. Therefore, there was no historical reference or guidelines to direct the Health Literacy Action Team efforts. There was an understanding that, at the end of the three-year period, all the Action Teams would offer some ideas for programs or projects that could be submitted for funding at the national level. The national ECOP Steering Committee charged all teams to:

- invite partners both internal and external to Extension as needed for maximum effectiveness,
- identify and develop systematic programs and curricula,
- engage colleagues in professional development, and
- assist with resource development.

Develop a Working Definition of Health Literacy

The majority of the Health Literacy Action Team members were unfamiliar with the Health Literacy topic area. Therefore, the first order of business was to find a working definition. The World Health Organization's (World Health Organization [WHO], 1998) definition laid the

responsibility of health literacy “within the motivation and ability of individuals to gain access and use information” (p. 10). As team members dug deeper into the issue, they discovered the WHO definition had been expanded upon by others and evolved to better encompass how health literacy is a component of the entire health care system.

The Calgary Charter on Health Literacy (2011) used a wider lens in defining health literacy, “Health literacy allows the public and personnel working in all health-related contexts to find, understand, evaluate, communicate, and use information.” Team members adopted this definition as more health care institutions are recognizing that the responsibility of improving health literacy lies not only with individuals but with all facets of the health care system such as pharmaceuticals, medical professionals, clinicians, health educators, the media and many others (Boulos, M. N. K., 2012; GB HealthWatch, 2018; USHHS, n.d.).

Identify Resources (Partners, Programs, and Curricula)

In the first year, Health Literacy Action Team members researched available resources in order to assess any gaps that might be addressed by Extension programs and curriculum. A spreadsheet database was created to capture information that might be of value as the team activities moved forward. The spreadsheet contained contact information for individuals identified by team members as being active and/or interested in health literacy. This included Extension health specialists, those working in private medical practice, university health educators, and public health professionals, among others.

In addition to listing partners, the spreadsheet identified health literacy programs and curricula; Extension delivered evidence-based programs that incorporated health literacy (e.g., chronic disease self-management educational programs, and Dining with Diabetes); publications; and links to institutions offering resources, toolkits, certification courses, and/or basic health literacy online tutorials. Fourteen major health literacy programs and curricula were identified through this research.

Engage Colleagues in Professional Development

At the same time as the Action Team members were conducting their research to identify resources, they also engaged colleagues in professional development to raise awareness of health literacy. At the national level, presentations were provided both within and outside Extension. Over a two-year period, activities included:

Webinars. “Understanding Health Literacy” presentations were hosted by eXtension (an online Extension resource), the American Association of Family and Consumer Sciences (AAFCS), and the National Extension Association of Family & Consumer Sciences (NEAFCS).

Oral presentations. Team members were invited speakers at national conferences (e.g., Epsilon Sigma Phi, Joint Council of Extension Professionals (JCEP), NEAFCS, the National Health Outreach Conference (NHOC), and health literacy conferences). A number of oral presentations conducted at the state and local levels involved departments of health, community health councils, university faculty, and health care professionals.

Based on the concept that education is enhanced through shared dialogue (Madron, 2008), the team members created polling questions to increase understanding in the concept of health literacy. These polling questions were integrated into the webinars and oral presentations. An example of a discussion scenario, polling questions, and discussions follows:

A 75-year old woman taking medication for hypertension began experiencing dizziness and nausea. She went to the Emergency Room where a doctor prescribed her another blood pressure pill. The woman had the medication filled and followed the doctor's directions for taking the medication. After three days, she was back in the Emergency Room.

Polling Question: What do you think happened?

- A. She took too much medication.
- B. She had a reaction to the medication.
- C. She only took one blood pressure pill and not the other.
- D. She wanted some attention.

Following group discussion, an explanation was provided by the Action Team: The doctor did not explain to the woman to take this new pill **in addition to** continuing her other blood pressure pill. She thought that since it was a "new" pill, she did not need to take the "old" pill.

Polling Question: Who is to blame for the mix up?

Responses that came out of the group discussion:

- The doctor for not explaining in greater detail.
- The patient for not asking if this is in addition to or replacing the other pill.

Health Literacy tri-fold informational brochure. An informational brochure was created to help raise awareness of the National Cooperative Extension's Framework for Health and Wellness and, specifically, health literacy. The brochure included the health literacy definition, descriptions on why health literacy is important, and how Extension is working to reach the

public through educational efforts focused on increasing health literacy. Team members' contact information were listed for those interested in sharing curricula, programs, and/or resources. The brochure was disseminated at conferences, presentations, poster sessions, health fairs, community events, and other venues.

Provide Assistance with Resource Development

After the first year of working together, the Health Literacy Action Team determined that the majority of available resources were written from a clinical perspective. Extension agents, educators, and community volunteers often do not come from a clinical, medical, or public health background. Therefore, the Action Team identified a need for resources that were more relevant for Extension professionals and others delivering programs in informal educational settings. The Action Team members wrote in an email message to the national ECOP Steering Committee (2016):

The Health Literacy (HL) Action Team members are exploring the possibility of developing a HL toolkit. There are resources currently available from the Centers for Disease Control and Prevention, and the Institute for Health Advancement. However, the team's impression is that these resources were developed more for those working within clinical settings. The proposed toolkit would better serve Extension educators and community volunteers who provide educational programs in informal settings such as community events. Guidelines available in the toolkit will be valuable when revising existing and/or developing new health-related messaging documents. After visiting with a few individuals serving in this capacity, the idea was met with much enthusiasm.

As the team continued identifying programs, they learned more about health literacy and types of training materials offered to the public. A team member shared an online course focused on health literacy and communications offered through Coursea, an Internet platform for online courses developed and offered by faculty from universities across the country that can be taken for college credit, certification, and professional development. With funding from the national ECOP Steering Committee, the Health Literacy Action Team members completed the 8-week online "Health Literacy and Communication for Health Professionals" Coursera course (<https://www.coursera.org/learn/health-literacy>), earning certificates of completion. The Coursera course was designed for public health professionals. So, while the information was educational, not all of it seemed conducive to community, informal programming.

The Action Team began considering a health literacy certificate course for Extension professionals, with the thinking that it could be released to the public at a later date. Through a member of the Steering Committee, the Action Team presented its idea to the director of the Horowitz Center for Health Literacy at the University of Maryland. The director accepted the

invitation to serve as an expert and resource for the development of the course. Unfortunately, all Action Teams were disbanded in 2017. Therefore, while there are individuals who remain interested in the concept, the health literacy certificate course has not yet made any progress.

Results and Impacts

Since its inception, the Health Literacy Action Team worked to raise awareness of health literacy, both within and outside Cooperative Extension, at the national level with the expectation of integrating health literacy into program areas and curricula. Participants attending the webinars and oral conference presentations presented by Action Team members provided feedback that was used to direct team activities in meeting the national ECOP Action Team goals that were listed in the Strategies and Process section of this article.

Using a Likert-type scale to measure participants' perceptions as to the importance of health literacy following oral presentations at two national conferences (i.e., NEAFCS and NHOC), results indicated that 78% of the respondents viewed health literacy as an important topic. When asked specifically about the importance of health literacy in Extension programming, 82% of the respondents believed it was important for Extension to address the topic.

Participants indicated ways they planned to use the presented health literacy information:

- Use more visuals in teaching lessons as a way to reach people with varying levels of health literacy.
- Enhance the reading comprehension on written materials.
- Consider audience literacy levels when creating handouts.
- Integrate health literacy guidelines when creating educational materials.
- Integrate into current work with a community coalition on Health Literacy to raise our county health ranking.

One individual can also make a difference. In her home state, a team member presented on Extension's role in health literacy to that state's Department of Health Chronic Disease Prevention Council Subcommittee. This led to a discussion and a small group of professionals forming a state Health Literacy Coalition. The founding members of the Coalition included:

- Department of Health Medical Director,
- Department of Health Promotion Coordinator,
- Extension Health Specialist (Action Team member),
- Health Literacy Specialist (private business),
- Medical Professional Advocate,
- Office of Health Equity Director,

- Office of Health Equity Outreach Coordinator, and
- University Medical Center Health Literacy Specialist.

Members of the Coalition determined that, in addressing social determinants of health, the state should include a health literacy component. As no activity in this area was evident, the Coalition is working towards a “health in all policies” approach to integrating health literacy into the state’s public policy. As the Coalition moves forward, more key partners will be invited to support the work of integrating health literacy for addressing health disparities.

Implications

Based on the experiences of the Health Literacy Action Team, it was determined that Extension professionals and educators view the topic of health literacy as very important to their work and feel it needs to be addressed in their programming. Accordingly, Extension professionals are encouraged to develop health literacy skills by way of educational programs offered in their communities or electronically. There are a number of excellent resources available that range from no cost to a nominal fee. Most notably are the resources available from the National Institutes of Health (NIH) Clear Communication website (NIH, 2017) and the Centers for Disease Control and Prevention (CDC) Health Literacy website (CDC, 2016). Certificates, often awarded upon completion of the educational modules, can be used to demonstrate knowledge in this area.

Health literacy coalitions created and/or supported at the campus level can offer practical training and easy to use methodology to enhance the oral and written communication skills of Extension professionals. The coalition members could include Extension health specialists, university health sciences teaching faculty, medical center teaching faculty, community volunteers from diverse populations, and media specialists, among others. Available at no cost are existing resources, (e.g., NIH and CDC) that can be used in setting up a program with tools easily modified to meet the needs of the educators.

Currently, the majority of health literacy educational modules and training programs are geared toward professionals in clinical settings. As Extension agents, program educators, and volunteers often do not have expertise in health sciences, their professional development needs are similar to but vary from the health literacy skills required in health care systems. Health literacy coalition members should be sensitive to the needs of Extension professionals, community health workers, *promotores*, and trained volunteers who are delivering health-related programs in informal settings.

Extension professionals are encouraged to work with the eXtension Creating Healthy Communities Community of Practice (CoP) to create a Health Literacy Subcommittee. The CoP

membership is comprised of health and wellness state Extension specialists, county Family and Consumer Sciences agents, program educators/coordinators, and other Extension faculty and staff. The Health Literacy subcommittee can offer continuing education and professional development through national webinars that are archived on the eXtension website. Further, for those interested in developing and offering the health literacy certificate course, the eXtension webinars might serve as a starting point for course content and could help in creating a system-wide approach for delivery.

Extension agents and educators using evidence-based programs and curricula developed by other institutions need to assess their applicability for use with the targeted audiences of their programs. In some instances, it may be prudent to pilot test program(s) with select audiences before offering it to the general public. In doing so, revisions can be made to ensure the program meets the needs and the health literacy levels of the intended audience.

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