Chapter 13
Health Literacy in Non–Communicable Diseases:
Contexts and Cases

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ABSTRACT

The chapter highlights some of the methods used to embed health literacy principles into patient outreach and education materials about non-communicable diseases: chronic conditions including mental health conditions. A person's or population's understanding and engagement with health represents its health literacy. Health literacy is a form social capital. The authors use an ecological, socially contextualized model of health literacy and demonstrate how it guides the structure and content of health education material in case examples from New York City, United States, and Greece in Europe. While the specific methods used in these cases vary, the essential principal is that it is critical to identify and build on information about an individual's health literacy contextualized in the individual's or group's socio-cultural and lived experiences. Only this way can an individual's or group's health literacy be advanced so that they can engage in behavior changes for both short- and long-term health outcomes.

INTRODUCTION

We are witnessing the making of a perfect storm. Social trends, local and global, are challenging the effectiveness of our health care system as well as patients' abilities to effectively manage their health information. The first trend is the growing number of individuals with one or more chronic conditions, particularly among underserved populations. Currently in the U.S. one-fifth (21%) of middle-aged adults have at least one chronic condition and the number of people managing chronic conditions is likely to increase given the growth in the older population, especially the "oldest old" (Freid, Bernstein, & Bush,

2012). The second trend is the growing diversity of the population and growing health inequality. The prevalence of chronic conditions is higher among underserved and minority populations (US Surgeon General, 2001; Sullivan Commission, 2005; Kessler, 2009). The third trend is the exponential growth of sources and modalities of health information available to patients. For example, patient-accessible Electronic Medical Records (EMRs) and Personal Health Records (PHRs) are proliferating in both small and large clinical practices and health care delivery systems in the US (ONC, 2015). So too, the number of health websites and eHealth and mHealth applications is also exploding. There are more than 40,000 medical, health and fitness apps available for smartphones and growing (Miller, 2013). All these trends present opportunities and challenges to patients, especially those who are underserved, under-educated, low health literate and ethnic minorities.

As clinicians have less time to spend with patients, and as medicine becomes more complex, patients are called upon to be more engaged and knowledgeable about their care. Patients and health consumers routinely have difficulty understanding information and performing routinely healthcare related tasks. These tasks include: tracking medical appointments, understanding health insurance coverage and medication and medication-taking regimens, understanding complex health conditions well enough to make informed decisions about behaviors and treatment options. These highlight the need for healthcare professionals and educators to understand as much possible about a patient's health literacy and how this is impacting how the patient can "manage" their health.

It is not uncommon for a patient with hypertension to say, "I can tell when my pressure is high because I get a headache" or for the asthmatic to say, "I only have asthma when I have an asthma attack." These remarks reveal much about the patient's understanding of their health (their health literacy). Dr. Ethan Halm, who studied a population of adult, underserved, asthmatics, found that these patients had either a functional understanding of the chronic nature of their condition, or they had an "episodic" understanding of their asthma. Episodic understanding describes the phenomenon of a person with a chronic health conditions who believes they only have the condition when they have symptoms. Halm's patients were less likely to perceive the importance of information about the use of inhaled corticosteroids and other means to "manage" their condition, and they had poor management of their condition (Halm, Mora, & Leventhal, 2006).

Unfortunately, the need to have patients play an active role in managing their health information and health has not been matched by health information and health management tools that are understandable to patients and reflect the health literacy and life experience of patients, especially underserved populations with low literacy and/or low health literacy (Lustria, Smith, & Hinnant, 2011; Sarkar et al., 2011). It is essential that health information and health information management tools are usable, useful and address the unique needs of the widest possible range of patient and provider populations (Britto et al., 2009; Krist & Woolf, 2011; Lazar, 2007). In order to achieve optimal outcomes, patients need to be health literate about their conditions (Baur, 2010; Davis et al., 2002; Koh et al., 2012; Schillinger, et al., 2003).

The lack of understanding of basic health and science information coupled with poor understanding of how to manage and treat a condition are fundamental characteristics of low health literacy. Almost thirty years of compelling evidence shows that low health literacy is associated with poorer patient engagement and management of their health, and poorer health outcomes. Low health literacy has been referred to as "the silent killer" (Zarcadoolas, Pleasant and Greer, 2005). A recent report by the European Centre for Disease Prevention and Control (ECDC) (Sixsmith, Doyle, D'Eath, & Barry, 2014) highlighted the 'evolving' concepts of health literacy, that "health literacy must be embedded in all population-level health initiatives at both a national and European level" (p. 3), calling among other things to have

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