

Easy to Write? Creating Easy-to-Read Patient Education Materials

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Background and Process

An Institute of Medicine (2004) report defined health literacy as “the degree to which individuals can obtain, process, and understand basic health information and services they need to make appropriate health decisions” (p. 1). Readers of easy-to-read materials are not limited to those with little education, those who speak English as a second language, and children. Most adults with low health literacy are white, native-born Americans (Parker, Ratzan, & Lurie, 2003). Individuals who need easy-to-read materials are in every race, ethnic, age, and income group.

Patients with cancer may have an increased risk of cognitive dysfunction compared with those who have never had the disease (Heflin et al., 2005). Cognitive dysfunction is a frequent finding in people with cancer, but it may go unnoticed. Cognitive problems result from many causes, including the direct effects of cancer on the central nervous system, indirect effects of certain cancers, and effects of cancer treatment on the brain. Mental and emotional aspects of dealing

with a cancer diagnosis (e.g., information overload, stress of living with a lack of predictive information and making treatment decisions, changes in schedule, anxiety, fear, financial pressure) also play a role.

People with limited health literacy generally have lower medication compliance rates, higher hospitalization rates, and worse health outcomes (Williams, Davis, Parker, & Weiss, 2002); therefore, the society’s easy-to-read materials are written to encourage and enable communication between patients and providers, as well as between patients and families, to motivate patients to follow health advice and reduce anxiety by helping them gain a sense of control. Approximately 153,000 easy-to-read English- and Spanish-language booklets have been distributed to date through the society’s Information Resource Center, its 68 chapters, and community health and cancer treatment facilities.

The initial draft of the myeloma booklet was based on the content of the society’s existing comprehensive myeloma booklet, which is updated regularly with the most recent diagnostic, treatment, and research information, for example *Williams Hematology’s* myeloma chapter (Barlogie, Shaughnessy, & Epstein, 2006). Many patients find the comprehensive booklet to be a valuable source of accurate and detailed information. However, for a considerable number of patients, especially the newly diagnosed, it is not the ideal resource because of its length and detail. The easy-to-read version presents the information over 32 pages, emphasizing key points about myeloma and its treatment in plain language, including brief explanations of medical terms, and incorporating graphics to convey ideas. The society’s patient services staff and medical director reviewed the draft for medical accuracy.

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Digital Object Identifier: 10.1188/07.CJON.506-510