

Healthcare Literacy: Multiple Perspectives Grounded in the Experience of Mexican American Caregivers

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Cancer caregivers in Mexican American families experience role-related challenges influenced by limited healthcare literacy. The lack of functional health literacy becomes complex when Mexican Americans have limited English proficiency (LEP) and cultural beliefs that contrast with those of the American healthcare system. Three sequential studies focused on assessing the experience of Mexican American, female cancer caregivers, including their role learning needs; evaluating available community learning materials; and identifying healthcare provider perceptions of caregiver learning needs. Study findings provide direction to improve the process and content of teaching to caregivers with LEP and other caregivers facing the crisis of cancer. Practice recommendations focus on development of targeted learning materials appropriate to caregiver-identified learning needs, language, and education level. Priority learning needs include strategies to meet patient needs for home medication administration, nutrition, and psychological support. Caregiver-preferred formats for learning include videotapes in a family-assisted setting and oral exchanges with other caregivers and care providers. Bilingual clinic personnel who partner with Mexican American family caregivers to address their literacy issues support positive health outcomes in this vulnerable population.

With recent dialogue about healthcare reform, addressing concerns about consumer healthcare literacy in the United States based on its relevancy to consumer safety and health outcomes is imperative (American Medical Association [AMA], 2008; Institute of Medicine [IOM], 2004; U.S. Department of Health and Human Services [USDHHS], 2000). Patients and families need sufficient literacy to access health information, recognize cues to seek help for health-related concerns, and navigate the healthcare system to find resources for care. Relevant to this article, healthcare literacy also means that consumers need to be able to complete health assessment forms, provide informed consent for care, read and implement prescribed drugs and treatments, and communicate effectively with healthcare providers to implement care regimens focused on improving healthcare outcomes (AMA, 2008; Medical Library Association, 2008; Rudd, 2002). Additionally, such literacy defines that consumers have the ability to advocate for self and others in promoting personal and community health to improve overall societal health (Kickbusch, 2002).

Evidence indicates that ethnic minorities (e.g., Mexican Americans), those who live in poverty, people who face unemployment, and those of advanced age often lack the healthcare literacy needed to fully participate in health promotion and

At a Glance

- ◆ Mexican American family caregivers experience role-related challenges influenced by limited health literacy and English proficiency, both of which block the understanding necessary to deliver high-quality care to their family members with cancer.
- ◆ Priority learning needs of Mexican American family cancer caregivers include ways to meet patient medication, nutrition, and psychological needs to support positive patient and caregiver outcomes during cancer treatment.
- ◆ Limited cancer information in formats accessible for Mexican American caregiver learning offers an opportunity for healthcare professionals, including nurses, to develop targeted materials and interventions that optimally meet the learning needs of Mexican American cancer caregivers.

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care (IOM, 2004; Lasater & Mehler, 1998; Schultz, 2002). In fact, limited health literacy predicts an older person's health outcome more than age, income, employment status, education, or race (Gazamararian et al., 1999; National Patient Safety Foundation, Partnership for Clear Health Communication, 2008). Those with limited health literacy are a vulnerable population because they often make personal errors in not seeking needed health care or make unsafe healthcare decisions. They often become "lost" in the care system or assume passivity without desired active involvement in care decisions, resulting in less than desirable health outcomes (Kripalani, Bengtzen, Henderson, & Jacobson, 2008; Rudd, 2002; USDHHS, 2000).

The lack of functional healthcare literacy may become more complex when consumers, including Mexican Americans, have limited English proficiency (LEP) and cultural beliefs that contrast with those of the American healthcare system. Such individuals lack health literacy because they are not fluent in English. In one study, only 17% of Spanish-speaking Hispanics actively sought cancer information as compared to 37% of English-speaking Hispanics and 48% of non-Hispanics (Vanderpool, Kornfeld, Rutten, & Squiers, 2009). LEP of Spanish-speaking people, including Mexican Americans, affects those individuals' ability to access information needed to develop disease understanding for participation in the healthcare process. Such individuals also may lack experience in the U.S. healthcare system, influencing their understanding of needed care to promote personal health (Atwood, 2008). Hispanic immigrants, 66% of whom are Mexican American (Ramirez & de la Cruz, 2002), assimilate less effectively into American culture than other ethnic groups and have LEP. They also have less access to health care than Hispanics who speak English and have adopted many American values and ways of living (Pew Hispanic Center & Robert Wood Johnson Foundation, 2008). Members of the Hispanic ethnic group are expected to experience a 142% increase in cancer activity by 2030 and continue to reflect high mortality rates, particularly for cervical and gastrointestinal cancers (American Cancer Society, 2007; Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009).

Even though evidence indicates that low-literacy populations disproportionately face the burden of chronic disease, the literature gives limited attention to assessment of literacy issues related to the care process. An urgent need exists to further examine healthcare access and quality-of-care issues, including the ability of Mexican American consumers with LEP and limited literacy to understand and participate in the care process related to their cultural values. LEP and limited literacy influence differences in health information seeking, perceptions, and behaviors that contribute to healthcare disparities among minority groups (Vanderpool et al., 2009). Examination of LEP and limited literacy becomes especially important based on the fact that Mexican Americans are the largest and fastest-growing U.S. minority group (Pew Hispanic Center & Robert Wood Johnson Foundation, 2008; U.S. Census News Bureau, 2009; USDHHS, 2000), and members of the Hispanic ethnic group are expected to experience a 142% increase in cancer by 2030 (Smith et al., 2009).

The purpose of this article is to discuss the findings of three interrelated studies on Mexican American caregivers of family members with cancer. The findings are relevant to literacy needs of caregivers and provide direction for improving the process

and content of disease teaching to caregivers with LEP and other caregivers facing the crisis of cancer.

Scope of the Problem

Despite evidence that health literacy benefits individuals and overall society, almost 44 million Americans (20%) are functionally illiterate (IOM, 2004). They lack sufficient interactive abilities of reading, writing, and computation to effectively manage their lives in a complex world and develop to their full potential (IOM, 2004; Rudd, 2002; Schultz, 2002). Even with sufficient literacy to manage home and work affairs, more than 98 million Americans struggle with the skills needed to understand the healthcare system and gain care for preventive, acute, and chronic health issues (USDHHS, 2000; Kutner, Greenberg, Jin, & Paulsen, 2006). Only 13% of the U.S. population, including most college graduates, possess "proficient" health literacy that supports their ability to understand pamphlet text, charts, graphs, and consent forms; compute drug dosages; and adhere to diabetic exchanges (Agency for Healthcare Research and Quality [AHRQ], 2008). Another 40% have "basic" health literacy and read at the sixth- to eighth-grade level (Rosales, 2008). Such people read and understand short documents related to healthcare screening but have difficulty completing long forms or reading patient health pamphlets. An additional 14% of the population has "below basic" health literacy. They face challenges in presenting for health appointments, following care regimens, and understanding or reading basic information. Many read at less than the fifth-grade level (Kutner et al., 2006; Rosales, 2008). Thirty percent of Hispanics, including most Mexican Americans, have "below basic" health literacy. An equal number of U.S.-born and foreign-born Mexican American adults also fall into this group (Rosales, 2008; Rudd, Kirsch, & Yamamoto, 2004).

Consumers with low healthcare literacy often have fewer years of education and lower personal income, factors which contribute to high rates of cardiovascular and communicable disease, late presentation for serious health issues, and overall low functional health even with control of socioeconomic variables (Weiss et al., 2005). Consumers with low literacy also face higher rates of hospitalization and complications, more injuries, and increased risk of death within five years as compared to people who successfully complete reading and computation tests on health (Atwood, 2008; Baker, Parker, Williams, & Clark, 1998; Center for Health Care Strategies, n.d.; Persell, Osborn, Richard, Skipkauskas, & Wolf, 2007; Rudd, 2002). People with low literacy, especially those with LEP, also have difficulty accurately describing health symptoms or completing health history forms to help providers make diagnoses (Roberts, 2008). This difficulty contributes to long clinic waits by patients, their perceptions of low-quality care, and increased costs of care (Atwood, 2008). Those with low literacy also have poor cancer screening knowledge and practices, leading to later-stage diagnosis when they access care (Lindau et al., 2002). In one study, one in four Hispanic adults lacked a consistent healthcare provider, despite almost half having health insurance. Many believed they were basically healthy and did not need preventive health care (Pew Hispanic Center & Robert Wood Johnson Foundation, 2008).

Even English-speaking people with low health literacy are less likely to follow medical directives because they minimize the importance of adherence. They often do not ask questions to increase their understanding of the importance of adherence or do not make appointments for follow-up care. They become overwhelmed with paperwork and authorization forms, which may affect their future healthcare access and health status (Atwood, 2008; Roberts, 2008). People with low literacy also have poor comprehension of informed consent, affecting sample sizes in research studies and clinical trials for diseases that more often affect those with LEP (Cox, 2002; Coyne et al., 2003; Kripalani et al., 2008; Sudore et al., 2006). LEP and low health literacy contribute to a lack of partnering between consumers and healthcare providers to reach healthcare goals; LEP and low health literacy also contribute to healthcare disparities identified among Hispanics and Mexican Americans and increased costs in the U.S. healthcare system (Atwood, 2008; Howard, Gazmararian, & Parker, 2005; Weiss & Palmer, 2004). Some of the cost evolves from increased numbers of lawsuits resulting from consumer perceptions of “rushed” health care, inadequate provider explanations of health problems, or inattention to consumers’ needs during healthcare visits (Harold, 2006). In some cases, consumers with LEP do not return for needed care because they perceive poor-quality care or, for Mexican Americans, care that does not meet their cultural values (Cagle, Wells, Hollen, & Bradley, 2007).

Limited research has examined current education materials for healthcare consumers with LEP, including those who speak Spanish. In one study involving low-literacy, English-speaking diabetics, only 34% of educational materials from the American Diabetic Association met a total of 32 criteria used to assess literacy of learning materials in English. The authors of the study emphasized that greater attention must be directed at reading level of materials, use of scientific jargon, font size, sentence length and structure, and visual organization of materials to increase their usefulness for patient education and better disease management (Hill-Briggs & Smith, 2008). Improving learning materials for those with LEP, including those who speak Spanish, seems particularly important.

The Current Studies

Three sequential studies focused on assessing the experience of Mexican American cancer family caregivers, including their learning needs to complete their role, available clinic and local community caregiver learning materials, and healthcare provider opinions about Mexican American family caregiver learning needs. The studies occurred over a three-year period, predominantly in a public oncology clinic serving diverse population groups with low health literacy, including Mexican Americans. All three studies received institutional review board approval from the researchers’ employment setting and the involved clinical system. In all studies, participants received gift cards to either Walmart or a grocery store to acknowledge their contribution.

Study 1: Exploring the Experience of Mexican American Cancer Family Caregivers

The researchers understood the need for study materials directed at low-literacy and Spanish-speaking populations before

the study began to gain accurate data to examine the phenomenon of interest. Informed consent forms and data-collection materials were available in English and Spanish and were at the sixth-grade reading level. Trained bilingual and bicultural undergraduate female students understood the cultural value of connecting with the Mexican American caregivers through conversation and read the forms needed for data collection (Cagle et al., 2007). The study implemented a mixed-method approach, using initial grounded theory to explore the experience of 34 middle-aged Mexican American family caregivers (see Table 1) involved in clinic care (Wells, Cagle, Bradley, & Barnes, 2008). Following qualitative analysis, a secondary analysis of quantitative data specific to assessment of mood, perceived health, and burden occurred (see Wells, Cagle, Bradley, Marshall, & Luna-Hollen [2009] for specifics).

Overall, caregivers identified anxiety, fatigue, and tenseness with caregiving but denied burden and problems with their personal health. However, 65% of caregivers scored high enough on the burden inventory to be at risk for depression (Wells et al., 2009). Study findings supported that caregivers “became stronger” as a result of their experience. In many ways, they demonstrated healthcare literacy by successfully navigating the healthcare system to advocate and find resources for an ill family member. Although they “became stronger” through caregiving, most caregivers expressed learning needs related to nutrition, medication management, and symptom complaints of the ill family member. The needs may have related to some caregivers needing translators to understand the care regimen and their role in that regimen, having “no money,” sometimes “getting sick,” and experiencing “uncertainty” about the cancer diagnosis and treatment process (Wells et al., 2008). Caregivers with LEP, a third of the sample who spoke or wrote only in Spanish, felt a particular urgency to find resources to meet their identified learning needs (see Table 1). As one caregiver noted, “That kind of education is not given to Hispanic people. Even less for people who do not speak English. We don’t know” (Wells et al., 2008).

Study 2: Describing Quality and Quantity of Cancer Caregiver Educational Materials

Based on the initial study findings, a second study focused on describing educational materials available in the public oncology clinic, two private oncology hospital libraries, a community cancer resource setting, and the local American Cancer Society office. Thirteen consumer or professional cancer Web sites also were examined for relevant materials meeting literacy, language, and learning needs of Mexican American caregivers based on findings from study 1.

The study involved training two bilingual and bicultural student research assistants (RAs) who surveyed agency educational materials and Web sites and organized their findings into categories. Collation of assessed materials produced the following categories: topic, supplier, publisher, Spanish availability, congruency of Spanish and English language materials, and relevancy to caregiver learning needs. Material collation also occurred according to material scientific accuracy, price, organizational layout, format (e.g., CD, pamphlet), use of illustrative anatomical drawings, and color to encourage participant reading and learning. All materials were assessed for English

Table 1. Comparison of Demographic Data Between Study 1 and 2

VARIABLE	STUDY 1 (MEXICAN AMERICAN CAREGIVER EXPERIENCE, N = 34)	STUDY 2 (CAREGIVER RESPONSE TO EDUCATIONAL MATERIALS, N = 11)
Age (years)	\bar{X} = 38.5, range = 21–63	\bar{X} = 41.6, range = 20–64
Years living in the United States	Range = 0.3–40	Range = 0.4–59
Born in Mexico	75%	72.7%
Hours of caregiving per day	Range = 0.3–24	\bar{X} = 7.66, range = 2.5–24
Speaks and writes only in Spanish	29.4%	63.6%

Note. An additional 64.7% (n = 22) of study 1 caregivers chose to complete interviews in Spanish, although they indicated that they spoke “mostly” English. This supports that 94.1% of caregivers (n = 32) felt more comfortable with their native language than English.

reading level via the Flesch-Kincaid Reading Ease Test (Microsoft® Word® 2003, version 11). A similar assessment of Spanish language materials could not be completed because of a lack of a tool to complete the activity. A Microsoft Office Access® 2003 (version 11) database cataloged information.

The initial part of the study located 145 educational materials relevant to cancer. Most focused on education of patients with cancer; few focused on caregiver learning. Materials consisted of books, pamphlets, Web sites, audio recordings, and videos. Of them, only 39% were available in Spanish and English. RAs noted poor or inaccurate translation from English to Spanish when they back-translated written materials. Upon viewing or listening to videos and audiotapes, the RAs expressed similar concerns. Many materials exceeded reading levels of ninth grade, perhaps preventing understanding of cancer and treatment by patients and caregivers. In 66% of agencies, materials specific to caregiver learning needs were difficult to find; online Spanish materials were particularly difficult to locate. In a subsample of 27 materials, 36% used medical terminology inappropriate to the literacy level of caregivers. Overall, the RAs struggled to find materials in most agencies or Web sites to meet Mexican American caregivers’ needs for learning about nutrition, medication, and symptom management for a family member with cancer.

The second part of the study involved caregiver response to selected learning materials in English and Spanish as presented by a bilingual RA during a caregiver’s clinic visit. The presentation helped develop insight into caregiver-preferred learning formats and needs. Caregiver recruitment occurred via flyers posted in the clinic. Demographic data forms indicated that the sample of 11 women provided care an average of 8 hours per day, most participants were middle-aged, and the sample was similar to that in the first study (see Table 1). To gain insight into caregiver-preferred learning formats, the RA used a structured survey to guide presentation of two different pamphlets to each caregiver. She was asked to voice her preference for format and appearance of the brochure that would gain her attention for learning. Responses of caregivers appear in Table 2. Through two different cycles of assessment involving different options in each cycle, caregivers chose among options that defined ways they learn best (see Table 3). Based on assessment of learning materials, caregivers noted that none addressed important topics for their understanding to provide quality care. The topics included ways to provide wound and injection care and ways to promote the emotional and physical comfort care of the patient.

Study 3: Assessing Healthcare Providers’ Perceptions of the Learning Needs of Mexican American Cancer Caregivers

The final study involved 20 healthcare providers employed in various roles at the clinic used for study 1. Most participants were certified nursing assistants (CNAs), licensed practical nurses or RNs, or receptionists, roles that connected them closely to ill family members and caregivers. Providers participated in one of three audiotaped focus groups, staffed by the first author and focused on gaining data about healthcare

providers’ understanding of the needs and experiences of Mexican American cancer caregivers. Participants had a mean age of 40.9 years, half had some college education, 75% were of Mexican American or African American heritage, more than 50% could not speak Spanish, and most had at least seven years of experience working with Mexican Americans (see Cagle & Wolff [2009] for specifics). Participants responded to four broad categories of questions with specific probes, including, “What are the learning needs of Mexican American female cancer caregivers?” and “How do clinic and other health services support learning and other needs of caregivers?” The process of data collection and analysis to meet qualitative rigor criteria appears elsewhere (Cagle & Wolff, 2009).

Caregiver Learning Needs and Cultural Context

Providers identified Mexican American cancer caregiver learning needs as “understanding the importance of getting and staying on cancer medications as prescribed by the doctor.” Providers perceived that Mexican American family caregivers needed education about side effects of certain patient medications, measures to control or prevent side effects, and when to call the doctor or clinic nurse if medications proved to be ineffective in meeting patient comfort needs. Providers noted that sometimes patients did not ever take their medications because of financial constraints, lack of understanding of the importance of taking medication, or a family caregiver’s belief that calling the doctor or clinic staff would show disrespect for the judgment of clinic personnel, the doctor in particular. Providers believed that caregivers also might fail to call the clinic about patient concerns between patient care appointments because it would “make” the caregiver look ignorant and contribute to a loss of desired caregiver empowerment. Such behavior frustrated staff because literacy and language differences between caregivers and staff influenced the latter’s ability to reassure caregivers and patients about health issues.

Literacy and LEP issues influenced Mexican Americans’ learning needs, according to clinic providers. Although five clinic providers were bilingual, the lack of a sufficient number of clinic translators and interpreters imposed significant barriers related to translation of medical information between clinic staff and Mexican American caregivers (Cagle & Wolff, 2009). Providers noted that patients used their own bilingual family members as translators if Spanish-speaking staff were not available. Clinic

staff acknowledged that the lack of professionally trained medical translators dramatically hindered their ability to meet a desired standard of care for Mexican American caregivers and families. Several providers noted that when a family member could not adequately translate information at a patient's clinic visit, the family member often omitted the information, preventing patient and caregiver understanding of the issue and contributing to a fear about cancer (Cagle & Wolff, 2009). Additionally, clinic providers mentioned that some Spanish-speaking patients "dreaded" coming to scheduled appointments because they knew no one would understand them and their learning needs would not be met.

LEP of caregivers affected their use of supportive clinic services such as social services, support groups, and nutritional consultation. Two full-time social workers in the clinic verified that Mexican American caregivers and families often left the clinic without fully understanding the plan of care and the value of social services. This may have resulted from a lack of understanding of the social worker role; adherence to a cultural value that only family members care for an ill family member, not outsiders; and competing life demands of the caregiver on patient clinic appointment days. Few Mexican American families had access to a nutritionist because that person worked only two days per week.

Clinic Approaches to Meeting Caregiver Needs

Providers indicated that the clinic supported Mexican American learning and other needs by "accommodating the caregiver and patient" and providing psychological and other support. The clinic staff saw patients according to appointment, but providers shared examples of "holding open an appointment" to allow a patient or caregiver to leave the clinic to eat or to allow other family members to be present for a patient's visit. Providers also planned care to avoid overloading the patient and family with information or procedures during a doctor's visit. Patient and caregiver teaching often occurred by providers demonstrating procedures caregivers would need to implement at home. According to providers, this psychomotor teaching (caregivers learning by doing) worked better than an oral teaching method when caregivers did not speak or understand English well. Staff believed this teaching approach helped caregivers gain a sense of competence so they could persevere during the cancer experience. Providers also noted that they provided pamphlets about cancer to educate caregivers. However, providers did not show concern that the materials included medical information at a high literacy level and focused on patient needs, not caregiver needs. Providers noted, however, that the clinic lacked handouts with pictures that illustrated ways to give injections and videos that would provide instructions to help caregivers provide better care to their loved ones.

Providers acknowledged that they attempted to support caregiver needs by providing psychological support to caregivers and encouraging them to be present at all clinic appointments to receive information about patient care and to ask questions. A weekly family support group in English and referral to local cancer care services were part of standard care. Providers saw themselves as supporting caregivers by emphasizing that cancer is not a form of punishment from God, thus dispelling a cultural belief held by Mexican Americans (Cagle & Wolff, 2009). Additional support by the two social workers, perceived as commit-

Table 2. Study 2 Caregiver Preferences for Brochure Format

PREFERENCE	n	%
Color brochure	8	77
Brochure with pictures about content	10	91
One-fold rather than two-fold brochure	5	45
Brochure in Spanish	5	45
Brochure in English and Spanish	4	36
Brochure in English	1	9
Brochure in either English or Spanish	1	9
N = 11		

ting themselves to fully assessing patient and caregiver needs, also appeared important to providers. Although neither social worker spoke Spanish, providers noted that each willingly offered information that could be translated by family members about ways to access discounted drugs and other financial and emotional support services for Mexican American caregivers and their families.

Discussion

The three interdependent studies offer some insight into learning needs of Mexican American cancer caregivers and literacy issues that influence the process and outcomes of care. Although the 34 caregivers in study 1 "became stronger," most journeyed through the caregiving experience with some unmet learning needs (Wells et al., 2008). The needs resulted from an absence of learning materials or materials that were not appropriate to caregiver language and educational level. Study 2 results support that most caregivers prefer to learn via videotapes and computers, particularly with family assistance with that learning. This may mean that caregivers depend on English-literate children and family members to interpret complex textual cancer content consistent with a reading level that meets caregiver learning needs. The fact that caregivers did not prefer reading about cancer and its treatment in the clinic or at home without family present may support the value of a learning intervention in the home in which each family member is an active participant.

A family intervention approach could incorporate the skills of each family member to learn and support one another during the cancer experience and meet the Mexican American cultural value of strengthening the family (Cagle et al., 2007). Interventions could be tailored to meet the needs of caregivers and families at diagnosis, throughout treatment challenges, and during patient recovery or palliative care (Coward & Kahn, 2004; Overcash, 2004). Caregivers need information to predict or more fully understand future care demands and ways to respond to the unpredictability of cancer (Hudson, 2006). Information packets specific to each stage of the cancer cycle could be produced and financed by pharmaceutical and foundation

Table 3. Study 2 Responses to Interview Questions

GROUPING AND ACTIVITY	N	%
"Please tell me which type of activity makes learning easier for you."		
First Grouping		
Reading	2	18
Listening to another caregiver	4	36
Reading or listening to someone else	5	45
Second Grouping		
Listening to an audiotape	—	—
Watching a video	10	91
Neither listening to an audiotape nor watching a video	1	9
Third Grouping		
Listening to an audiotape	1	9
Listening and seeing a nurse or caregiver on a video doing care or talking	10	91
"Please tell me which type of activity makes learning easier for you."		
First Grouping		
Learning on a computer at home	6	55
Learning on a computer at the clinic	2	18
Neither listening on a computer at home nor learning on a clinic computer	3	27
Second Grouping		
Listening to audiotapes at home	6	55
Listening to audiotapes at the clinic	2	18
Neither listening to audiotapes at home or the clinic	3	27
Third Grouping		
Talking to other caregivers	5	45
Reading at the clinic	1	9
Reading at home with family	5	45
N = 11		

support. Short homework assignments, either written by clinic staff or accessed on specific Web sites, and family discussion of videos also might address learning needs of caregivers and families between clinic visits. Telephone follow-up by healthcare providers to assess caregiver understanding of content might help reinforce learning, emphasize the need for continued patient follow-up, and prepare caregivers for the next patient appointment. Any translators used in family interventions must have experience with the interventions, be fully bilingual and knowledgeable about the subject, and be willing to work with providers and caregivers for quality translation that allows continuity of care (Rosales, 2008). Study 2 reinforced the finding that caregivers desire learning from other caregivers and providers of care, lending evidence to the value of regular English and Spanish caregiver support groups during the cancer cycle to decrease caregiver uncertainty and provide hope. Such groups could involve family members and reinforce teaching provided during patient clinic visits. Bilingual and bicultural community health workers (*las promotoras*) could collaborate with providers to help bridge Mexican American cultural values and learning styles with current biomedical approaches to patient teaching (Cagle & Wolff, 2009). The workers also might nurture, in a culturally sensitive manner, seeking of preventive health screening by Mexican American caregivers to support their health for continued family care. Such preventive behaviors remain uncommon in Mexican American women for a variety of reasons (Coleman et al., 2003; Yarbrough, 2004).

Study 2 also indicated that caregivers desire more materials relevant to their reading level of approximately seventh grade based on the facts that most people read two grades below their last year of completed education and that most laypersons read healthcare information at a fifth-grade level (Rudd et al., 2004). Caregivers also desired more videos for learning, material availability in English and Spanish, and arrangement of the clinic waiting area to accommodate learning from other caregivers and family members. With 80% of Hispanics gaining health information from television or radio (Pew Hispanic Center & Robert Wood Johnson Foundation, 2008), caregivers also might benefit from clinic television information on cancer care. Clinic signage in Spanish as well as English to direct caregivers and family members to available educational materials also would help caregivers meet their learning needs.

Providers in study 3 acknowledged long clinic waits for patients and family caregivers; caregiver frustration with financial and legal issues, such as gaining patient services when a patient is undocumented; and language barriers that required consistent access to clinic translators. Providers noted they often would "accommodate" a patient and caregiver by collaborating with them to meet cultural learning needs via demonstration when language differences existed between Mexican American caregivers and providers. However, providers agreed that the clinic needed more social workers, bilingual staff, and educational materials in Spanish to meet the literacy needs of patients and their families (Cagle & Wolff, 2009). Additional RNs with a scope of practice to teach patients might expand the limited teaching provided by less-educated personnel (i.e., CNAs) to meet the needs of people with LEP.

Recent concerns about the quality of healthcare delivery and healthcare disparities among low-literacy populations have stimulated various initiatives focused on prioritizing the improvement of consumer health literacy, including those with LEP such as Mexican American caregivers and families (Joint Commission, 2009). The nurse's teaching role should focus on initial assessment of the consumer's level of healthcare literacy and later development and evaluation of a plan to meet healthcare needs based on consumer assessment at each health visit. Initial assessment may involve use of the REALM tool (Rapid Estimate of Adult Literacy in Medicine) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999) to assess functional health literacy, knowing that providers often overestimate patient literacy skills (Lindau et al., 2002). After assessment, experts note, educational materials for LEP groups must receive validation in a carefully selected trial setting to ensure that they accurately address recipient learning needs, not provider needs, and reflect active partnerships among patient, family, and provider (Mika, Wood, Weiss, & Treviño, 2007; National Patient Safety Foundation, Partnership for Clear Health Communication, 2008; USDHHS, n.d.; Weiss et al., 2005). Staff education to effectively use materials also should occur prior to use (Mika et al., 2007; Rosales, 2008; Weiss et al., 2005). Other helpful hints to meet learning needs of patients with LEP and low literacy levels, as recommended by several governmental quality organizations focused on consumer health literacy (AHRQ, 2008; National Quality Forum, 2005), appear in Figure 1.

Cancer caregivers need understandable information that meets their needs for coping during a difficult time of patient

symptom management and comfort care (Haley, 2003). Providers must help caregivers access and gain understanding of cancer so they can help their ill family members during care. In many treatment facilities, this supports adequate numbers and quality of bilingual staff, translators, and diverse discipline personnel who deliver an interdisciplinary approach to family cancer care. In one study, 83% of Spanish-speaking Hispanics had never looked for information on cancer as compared to 52% of non-Hispanics. Of those Spanish-speaking people, approximately 30% had little or no confidence in their ability to find cancer information as compared to 6% of non-Hispanics and 11.5% of English-speaking Hispanics. Among Spanish-speaking Hispanics, 67% noted that their search for cancer information was difficult, and twice as many expressed difficulty in understanding information as compared to English-speaking Hispanics (Vanderpool et al., 2009). Despite such difficulty, Mexican American caregivers, based on their respect and trust of doctors and healthcare providers in general (Wells et al., 2008), may not ask questions during care or phone calls to the treatment agency between visits. They should be encouraged to ask questions and seek resources from providers and perhaps other knowledgeable caregivers to better understand cancer materials and patient symptoms that influence patient and caregiver coping. Providers must ensure that educational and support materials value Mexican American family decisions but also encourage an active partnership with caregivers and families to meet their needs (Cagle & Wolff, 2009).

With a proliferation of patient-centered Web sites, providers may need to help caregivers and families evaluate sites for valid information to meet their learning needs (Alexander, 2002). Several studies have indicated that non-Hispanic consumers use online learning resources more than English-speaking Hispanics and that Spanish-speaking Hispanics use the Internet infrequently (Davis, Diaz-Mendez, & Garcia, 2009; Vanderpool et al., 2009). Davis et al. (2009) found that low use of the Internet occurred in a sample of 40 Spanish-speaking cancer survivors because they feared “feeling bad” as a result of seeking information, much of it in English. Although a wealth of information on cancer treatment and prevention is available online, few Web sites provide such information in Spanish. Providers may wish to help caregivers access the National Cancer Institute Web site, which provides culturally and linguistically appropriate cancer information (visit www.cancer.gov/espanol). Continued work to assess and

respond to the unique needs and cultural meaning of cancer of Spanish-speaking and Hispanic populations remains a strong focus of the American Cancer Society and the National Cancer Institute (Health Information National Trends Survey, 2009).

Since completion of the studies, the public oncology clinic has undergone renovation, and a separate area provides access to educational pamphlets. However, many of the materials continue to be available only in the English language; limited financial resources provide a barrier to the purchase of materials in Spanish. Author consultation with new administrative staff has allowed receipt of some free educational materials from pharmaceutical companies and foundations focused on health literacy. Use of bilingual community health workers, through a strong coalition supported by a local medical school, can help to generate materials and translate current materials from English to Spanish.

Conclusion

As advocates for healthcare consumers, healthcare providers, including nurses, have an obligation to help consumers with low literacy and LEP in understanding health issues and finding resources that will improve their overall health and that of their families (Schultz, 2002). Ensuring health literacy for each consumer of health care is an issue of fairness and is a basic human right, according to *Healthy People 2010* (USDHHS, 2000). Overall, healthcare providers must acknowledge the reality that healthcare outcomes suffer because of limited consumer healthcare literacy, particularly for those with LEP. This includes Mexican American cancer caregivers who continue to struggle to convey their care needs, based on evidence that this group has low levels of cancer information-seeking, which may influence their ability to effectively care for a family member with cancer. With projections that increasing numbers of Hispanics, including Mexican Americans, will experience cancer in the future and require family caregiving, focus must be placed on ways to partner with Mexican American caregivers and their families to bolster their understanding of the cancer trajectory for improved family outcomes.

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- Compose forms to meet a sixth-grade to seventh-grade reading level.
- Use a minimum of a 14-point font.
- Use paragraphs with two to three sentences.
- Define words in simple language.
- Use active voice, rather than passive voice.
- Include metaphors, cartoons, and illustrative quotations to connect to consumers' personal lives.
- Use sentences with 10 or fewer words.
- Emphasize pictures and bullets to illustrate important content.
- Use a “teach-back” method for clinical visits.

Figure 1. Suggestions for Developing Materials for Patients With Low Literacy or Limited English Proficiency

References

- Agency for Healthcare Research and Quality. (2008). *Agency news and notes: Only about 1 in 10 adult Americans have all the skills needed to manage their health*. Retrieved from <http://www.ahrq.gov/research/jul08/0708RA41.htm>
- Alexander, K. (2002). A selected list of Spanish language and low literacy patient education Web sites. *Journal of Pediatric Health Care, 16*, 151-155. doi: 10.1067/mpH.2002.124104
- American Cancer Society. (2007). *Cancer facts and figures for Hispanic/Latinos 2006-2008*. Atlanta, GA: Author.
- American Medical Association. (2008). *American Medical Association: Health literacy*. Retrieved from <http://www.ama-assn.org/ama/pub/category/8115.html>
- Atwood, C.A. (2008). Health literacy: Do your patients really understand? *AACN Viewpoint, 30*(2), 3-5. Retrieved from http://findarticles.com/p/articles/mi_qa4022/is_200803/ai_n25419742/
- Baker, D.W., Parker, R.M., Williams, M.V., & Clark, W.S. (1998). Health literacy and the risk of hospital admission. *Journal of General Internal Medicine, 13*, 791-798. doi: 10.1046/j.1525-1497.1998.00242.x
- Baker, D.W., Williams, M.V., Parker, R.M., Gazmararian, J.A., & Nurss, J. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling, 38*, 33-42. doi: 10.1016/S0738-3991(98)00116-5
- Cagle, C.S., Wells, J.N., Hollen, M.L., & Bradley, P. (2007). Weaving theory and literature for understanding Mexican American caregiving. *Hispanic Health Care International, 5*(4), 149-161.
- Cagle, C.S., & Wolff, E. (2009). Blending voices of Mexican American cancer caregivers and healthcare providers to improve care. *Oncology Nursing Forum, 36*, 555-562. doi: 10.1188/09.ONF.555-562
- Center for Health Care Strategies. (n.d.). *Health literacy fact sheet*. Lawrenceville, NJ: Author. Retrieved from http://www.chcs.org/usr_doc/Health_Literacy_Fact_Sheets.pdf
- Coleman, E.A., Lord, J., Heard, J., Coon, S., Cantrell, M., Mohrman, C., & O'Sullivan, P. (2003). The Delta Project: Increasing breast cancer screening among rural minority and older women by targeting rural healthcare providers. *Oncology Nursing Forum, 30*, 669-677. doi: 10.1188/03.ONF.669-677
- Coward, D.D., & Kahn, D.L. (2004). Resolution of spiritual disequilibrium by women newly diagnosed with breast cancer [Online exclusive]. *Oncology Nursing Forum, 31*, E24-E31. doi: 10.1188/04.ONF.E24-E31
- Cox, K. (2002). Informed consent and decision-making: Patients' experiences of the process of recruitment to phases I and II anti-cancer drug trials. *Patient Education and Counseling, 46*, 31-38. doi: 10.1016/S0738-3991(01)00147-1
- Coyne, C.A., Xu, R., Raich, P., Plomer, K., Dignan, M., Wenzel, L.B., . . . Cella, D. (2003). Randomized, controlled trial of an easy-to-read informed consent statement for clinical trial participation: A study of the Eastern Cooperative Oncology Group. *Journal of Clinical Oncology, 21*, 836-842. Retrieved from <http://jco.ascopubs.org/cgi/reprint/21/5/836>
- Davis, S.W., Diaz-Mendez, M., & Garcia, M.T. (2009). Barriers to seeking cancer information among Spanish-speaking cancer survivors. *Journal of Cancer Education, 24*, 167-171. doi: 10.1080/08858190902873053
- 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. Retrieved from <http://jama.ama-assn.org/cgi/content/full/281/6/545>
- Haley, W.E. (2003). Family caregivers of elderly patients with cancer: Understanding and minimizing the burden of care. *Journal of Supportive Oncology, 1*(Suppl. 2), 25-29. Retrieved from <http://www.supportiveoncology.net/journal/articles/0104s225.pdf>
- Harold, T.K. (2006). Minimizing medical litigation—Part I. *Journal of Medical Practice Management, 21*, 192-199.
- Health Information National Trends Survey. (2009). Brief 12: Hispanics less likely to seek cancer information than non-Hispanics. Retrieved from http://hints.cancer.gov/brief_12.jsp?t=brief12
- Hill-Briggs, F., & Smith, A.S. (2008). Evaluation of diabetes and cardiovascular disease print patient education materials for use with low-health literate populations. *Diabetes Care, 31*, 667-671. doi: 10.2337/dc07-1365
- Howard, D.H., Gazmararian, J., & Parker, R.M. (2005). The impact of low health literacy on the medical costs of Medicare managed care enrollees. *American Journal of Medicine, 118*, 371-377. doi: 10.1016/j.amjmed.2005.01.010
- Hudson, P.L. (2006). How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support? *Journal of Palliative Medicine, 9*, 694-703. doi: 10.1089/jpm.2006.9.694
- Institute of Medicine. (2004). *Health literacy: A prescription to end confusion*. Washington, DC: National Academies Press.
- Joint Commission. (2009). Facts about patient-centered communication. Retrieved from http://www.joint-commission.org/PublicPolicy/facts_health_literacy.htm
- Kickbusch, I. (2002). Health literacy: A search for new categories. *Health Promotion International, 17*(1), 1-2. Retrieved from <http://heapro.oxfordjournals.org/cgi/content/full/17/1/1>
- Kripalani, S., Bengtzen, R., Henderson, L.E., & Jacobsen, T.A. (2008). Clinical research in low-literacy populations: Using teach-back to assess comprehension of informed consent and privacy information. *IRB: Ethics and Human Research, 30*(2), 13-19. Retrieved from <http://www.thehastingscenter.org/Publications/IRB/Detail.aspx?id=928>
- Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy (NECS 2006-483)*. Retrieved from <http://nces.ed.gov/pubs2006/2006483.pdf>
- Lasater, L., & Mehler, P.S. (1998). The illiterate patient: Screening and management. *Hospital Practice, 33*(4), 163.
- Lindau, S.T., Tomori, C., Lyons, T., Langseth, L., Bennett, C.L., & Garcia, P. (2002). The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multi-ethnic cohort of women. *American Journal of Obstetrics and Gynecology, 186*, 938-943. doi: 10.1067/mob.2002.122091
- Medical Library Association. (2008). *Health information literacy*. Retrieved from <http://www.mlanet.org/resources/healthlit>
- Mika, V.S., Wood, P.R., Weiss, B.D., & Treviño, L. (2007). Ask me 3: Improving communication in a Hispanic pediatric outpatient practice. *American Journal of Health Behavior, 31*(Suppl. 1), S115-S121. Retrieved from <http://www.atypon-link.com/PNG/doi/pdf/10.5555/ajhb.2007.31.supp.S115>
- National Patient Safety Foundation, Partnership for Clear Health Communication. (2008). About the Partnership for Clear Health Communication. Retrieved from <http://www.npsf.org/pchc/about-the-partnership-php>
- National Quality Forum. (2005). *Improving patient safety through informed consent for patients with limited health literacy*. Washington, DC: Author.

- Overcash, J.A. (2004). Using narrative research to understand the quality of life of older women with breast cancer. *Oncology Nursing Forum*, 31, 1153-1159. doi: 10.1188/04.ONF.1153-1159
- Persell, S.D., Osborn, C.Y., Richard, R., Skipkauskas, S., & Wolf, M.S. (2007). Limited health literacy is a barrier to medication reconciliation in ambulatory care. *Journal of General Internal Medicine*, 22, 1523-1526. doi: 10.1007/s11606-007-0334-x
- Pew Hispanic Center & Robert Wood Johnson Foundation. (2008). Hispanics and health care in the United States. Retrieved from <http://www.rwjf.org/pr/product.jsp?id=33486>
- Ramirez, R.R., & de la Cruz, G.P. (2002). *The Hispanic population in the United States: March 2002. Current population reports*. Washington, DC: U.S. Census Bureau. Retrieved from <http://www.census.gov/prod/2003pubs/p20-545.pdf>
- Roberts, D. (2008). Nursing antidotes for poor health literacy [Editorial]. *MedSurg Nursing*, 17(2), 75.
- Rosales, A. (2008, May 6). *Untangling culture, literacy, and language for effective cancer communication*. Presentation at the 6th Biennial Conference: Cancer, Culture and Literacy, Moffitt Cancer Center, Clearwater Beach, FL.
- Rudd, R., Kirsch, I., & Yamamoto, K. (2004). *Literacy and health in America*. Princeton, NJ: Educational Testing Services, Center for Global Assessment Policy Information Center. Retrieved from <http://www.ets.org/Media/Research/pdf/PICHEATH.pdf>
- Rudd, R.E. (2002). Literacy and implications for navigating health care. Retrieved from http://www.hsph.harvard.edu/healthliteracy/slides/2002/2002_01.html
- Schultz, M. (2002). Low literacy skills needn't hinder care. *RN*, 65(4), 45-48.
- Smith, B.D., Smith, G.L., Hurria, A., Hortobagyi, G.N., Buchholz, T.A. (2009). Future of cancer incidence in the United States: Burdens upon an aging, changing nation. *Journal of Clinical Oncology*, 27, 2758-2765. doi: 10.1200/JCO.2008.20.8983
- Sudore, R.L., Landefeld, C.S., Williams, B.A., Barnes, D.E., Lindquist, K., & Schillinger, D. (2006). Use of a modified informed consent process among vulnerable patients: A descriptive study. *Journal of General Internal Medicine*, 21, 867-873. doi: 10.1111/j.1525-1497.2006.00535.x
- U.S. Census News Bureau. (2009, May 14). Census Bureau estimates nearly half of children under age 5 are minorities. Estimates find nation's population growing older, more diverse. Retrieved from <http://www.census.gov/Press-Release/www/releases/archives/population/013733.html>
- U. S. Department of Health and Human Services. (n.d.). Plain language: A promising strategy for clearly communicating health information and improving health literacy. Retrieved from <http://www.health.gov/communication/literacy/plainlanguage/PlainLanguage.htm>
- U.S. Department of Health and Human Services. (2000). *Healthy People 2010. Understanding and improving health*. Retrieved from <http://www.healthypeople.gov/Document/pdf/uih/2010uih.pdf>
- Vanderpool, R.C., Kornfeld, J., Rutten, L.F., & Squiers, L. (2009). Cancer information-seeking experiences: The implications of Hispanic ethnicity and Spanish language. *Journal of Cancer Education*, 24(2), 141-147. doi: 10.1080/08858190902854772
- Weiss, B.D., Mays, M.Z., Martz, W., Castro, K.M., DeWalt, D.A., Pignone, M.P., . . . Hale, F.A. (2005). Quick assessment of literacy in primary care: The newest vital sign. *Annals of Family Medicine*, 3, 514-522. doi: 10.1370/afm.405
- Weiss, B.D., & Palmer, R. (2004). Relationship between health care costs and very low literacy skills in a medically needy and indigent Medicaid population. *Journal of the American Board of Family Practice*, 17, 44-47. Retrieved from <http://www.jabfm.org/cgi/content/full/17/1/44>
- Wells, J.N., Cagle, C.S., Bradley, P., & Barnes, D. (2008). Voices of Mexican American caregivers for family members with cancer: On becoming stronger. *Journal of Transcultural Nursing*, 19(3), 223-233. doi: 10.1177/1043659608317096
- Wells, J.N., Cagle, C.S., Bradley, P., Marshall, D., & Luna-Hollen, M.L. (2009). Perceived mood, health, and burden in female Mexican American family cancer caregivers. *Health Care for Women International*, 30, 629-654. doi: 10.1080/07399330902928857
- Yarbrough, S.S. (2004). Older women and breast cancer screening: Research synthesis [Online exclusive]. *Oncology Nursing Forum*, 31, E9-E15. doi: 10.1188/04.ONF.E9-E15

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Journal Club Discussion Questions

This article has been identified as appropriate for a journal club. When you read this article, think about how you would change your current practice regarding osteoporosis in your patients. See the Evidence-Based Practice column in the February 2009 *Clinical Journal of Oncology Nursing* (Vol. 13, No. 1, pp. 109-112) on how to implement and participate in journal clubs. Photocopying of this article for discussion purposes is permitted.

1. What is the clinical practice question the authors are trying to address?
2. Is the purpose of the article described clearly?
3. Is the literature review comprehensive, and are major concepts identified and defined?
4. What percentage of your cancer population is Mexican American or Hispanic?
5. How do you assess health literacy?
6. What do you do differently when you have concerns about the ability of a patient or family to comprehend information?
7. Do you have a variety of patient education materials available in Spanish?
8. How do the author's recommendations compare to your current practice?
9. What practice change recommendations will you make based on the evidence presented in this article?