

Blending Voices of Mexican American Cancer Caregivers and Healthcare Providers to Improve Care

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A large percentage of the U.S. population provides informal care to an ill family member, supporting an urgent need for nursing research to explore the caregiving experience and its influence on caregiver health and family functioning (Moore, Moire, & Patrick, 2004; Northouse, Kershaw, Mood, & Schafenacker, 2005). A caregiver's culture affects the care experience and influences family relationships in the context of illness. In Mexican American culture, women, typically the eldest daughter, become caregivers to ill family members because of a cultural priority of family (Ayalong, 2004; Wells, Cagle, & Bradley, 2006). A recent grounded theory study found that 34 Mexican American family caregivers identified positive outcomes of caregiving, including "becoming stronger." "Becoming stronger" referred to patients receiving quality care; increased family closeness; and strengthening of caregiver faith, knowledge, and satisfaction with self. All women, however, identified times of "hurting too much" if they lacked understanding of cancer care because of factors associated with the cultural meaning of cancer: limited literacy, English-speaking ability, financial resources, or social support for their role (Wells et al., 2006; Wells, Cagle, Bradley, & Barnes, 2008).

Like Mexican American family caregivers, healthcare providers function in a culture—a system of shared values, norms, and beliefs informed by experiences and education that organize behavior and personal choices (Leininger & McFarland, 2002; Sheldon, 2005). Whether provider-caregiver interactions are influenced when family caregivers of patients with cancer and their healthcare providers hold similar values, beliefs, and knowledge that contribute to the meaning of cancer for both groups is unclear. Limited understanding of common perceptions of caregivers and providers may contribute to misperceptions of needed care by both groups, including provision of educational, resource, and emotional support interventions to help Mexican American family caregivers

Purpose/Objectives: To identify and categorize healthcare provider perceptions of the meaning of cancer to Mexican American female family caregivers, including comparisons to caregiver themes in previous research.

Research Approach: Descriptive, qualitative.

Setting: Three focus groups held in a publicly funded cancer clinic in the southwestern United States.

Participants: 20 healthcare providers in diverse roles.

Methodologic Approach: Tape recording of focus group discussions and transcription of content produced textual data for individual and team analysis.

Main Research Variables: Healthcare provider understanding, caregiver learning, and support needs.

Findings: Five major themes emerged related to the meaning of cancer to Mexican American caregivers: Caregivers fear the cancer diagnosis, interpret cancer as punishment, value maintenance of hope, believe in God and the doctor, and selectively disclose medical information.

Conclusions: Healthcare providers identified most themes defined by Mexican American caregivers in an earlier study. However, provider identification of additional themes supports a blending of voices and partnerships between Mexican American cancer caregivers and providers to address caregiver literacy and support needs during the cancer cycle.

Interpretation: Understanding the cultural meaning of cancer to Mexican American caregivers provides a foundation for healthcare providers to define appropriate caregiver interventions in the cancer trajectory and to meet caregiver support and learning needs. Partnering of caregivers and providers also can ensure culturally sensitive care for Mexican American families experiencing cancer.

during cancer (Barrett, Puryear, & Westpheling, 2008; Gordon, 2004). Therefore, a qualitative study focused on healthcare providers' understanding of Mexican American female cancer caregivers' meaning of cancer. Study questions explored meaning from a provider perspective, including how meaning influenced caregivers "becoming

stronger” or “hurting too much” during caregiving and ways clinic services could better serve the needs of caregivers of patients with cancer. This article will focus on one of five research questions of the larger study: How do healthcare providers perceive the learning and support needs of Mexican American female caregivers of family members with cancer based on their ethnic definition of cancer? An understanding of this question, informed by an overview of the cultural context of cancer in the Mexican American community and findings of the grounded theory study, allow a blending of caregiver and provider perspectives to support an intervention with Mexican American female caregivers who respond to the needs of their loved one with cancer as their priority role.

Background

Limited literature has explored the meaning of cancer among Mexican American caregivers as compared to other ethnic groups (Cagle, Wells, Hollen, & Bradley, 2007; Phillips, Torres de Ardon, Kommenich, Killeen, & Rusinak, 2000; Pinquart & Sorenson, 2005). Cultural values and beliefs most likely influence appraisal of the cancer caregiving experience, and the sociocultural context of the women’s lives provides additional meaning. Caregiver adherence to key cultural values of “always maintaining hope,” even in situations defined as fatal, and use of the family as social support may buffer Mexican American caregivers of patients with cancer from negative role outcomes (Frank et al., 2002; Juarez, 2003; Wells et al., 2008). A Mexican American caregiver may honor a strong cultural value to protect the patient from emotional distress and promote family hope by not disclosing a cancer diagnosis (Ayalong, 2004; Sheldon, 2005). A strong belief that God will care for the patient (Juarez, Ferrell, & Borneman, 1998), “it is God’s will” that the patient has cancer (Ashing-Giwa et al., 2004), or that the doctor is an extension of God and will cure the patient, may soften the stressors of a cancer diagnosis and needed life restructuring to respond to the diagnosis (Wells et al., 2008). Additional cultural values and beliefs to support the family, particularly ill members, include family welfare over individual welfare, traditional gender roles, some acceptance of paternalistic values (“machismo”) (Hamner & Turner, 1996), and a holistic definition of health support positive appraisal of caregiving by Mexican American women (Crist, Garcia-Smith, & Phillips, 2006; Mendelson, 2002). The values appear particularly strong among Mexican American women of low acculturation who often deny caregiver burden (Borrayo, Lawsins, & Coit, 2005; Cagle et al., 2007; Fernandez, Palmer, & Leong-Wu, 2005) but suffer with a belief that cancer is fatal and reflects “punishment from God” (Allison, Duran, & Pena-Purcell, 2005; Schettino, Hernandez-Valero, Moguel, Hajek, & Jones, 2006).

However, sociocultural factors present in a Mexican American female caregiver’s life may influence the mean-

ing she attaches to cancer and her role. The caregiver may find her family expects her to assume her unpaid role even if it means quitting her paid job (Wells et al., 2008), which could cause loss of needed family income, more intergenerational conflict related to acculturation of the caregiver (Cagle et al., 2007), and lower caregiving role satisfaction (Jolicoeur & Madden, 2002; Sabogal, Marin, & Otero-Sabogal, 1987). Less satisfaction may generate caregiver perception of “too much,” particularly if a caregiver perceives a high degree of uncertainty and limited social support as a loved one’s health deteriorates through the illness process (Matthews, 2003; Northouse et al., 2002; Wells et al., 2008). The perceptions may cause caregiver distress that further hinders patient coping (Cagle et al.; Northouse, Templin, & Mood, 2001). Caregiver distress causes personal fatigue, sleep disturbances, and physical ailments that influence overall health and contribute to possible perceptions of caregiving burden (Carter, 2006; Swore Fletcher, Dodd, Schumacher, & Miaskowski, 2008; Wells et al., 2008). Further sociocultural issues such as limited literacy, lack of healthcare access because of transportation or undocumented status, or limited English proficiency to learn about cancer also may contribute to uncertainty and ability to partner with healthcare providers (Hubbell, 2006; Matthews; Northouse et al., 2005).

An examination of the literature showed no studies relevant to perceptions of healthcare providers, including nurses, who assess and intervene with Mexican American caregivers of family members with cancer. To provide culturally sensitive care and address healthcare disparities that result from lack of partnerships between providers and recipients of care (Kline, 1999), providers must use generic caring (caring grounded in culturally relevant practices) and therapeutic caring (caring learned and practiced based on professional and informal experience) to meet a caregiver’s or group’s needs and care (Leininger & McFarland, 2002). A connection of the two care aspects, in partnership with family caregivers, will produce beneficent and meaningful care of culturally diverse caregivers and generate needed knowledge for a culturally sensitive care intervention.

Methods

Research Approach

A qualitative, descriptive design using focus group methodology addressed the research question of the study. The approach seemed relevant because focus groups have the capability to produce rich data as a function of creation of a nonthreatening environment for diverse group discussions (Berg, Cromwell, & Arnett, 2002; Shah, Coyle, Kavanaugh, Adams-Hult, & Lipsky, 2004).

The primary author invited healthcare providers in a public cancer clinic, used in the earlier grounded theory study, to participate. Participant inclusion criteria

included an ability to speak English, aged 21 years or older, and clinic employment involving direct interaction with Mexican American patients with cancer and their caregivers. Efforts were made to obtain a mix of providers (diverse in role, preparation, and ethnicity) to gain a multiperspective understanding of provider beliefs about the meaning of cancer to caregivers and their learning and support needs.

Procedures

The human safeguards committees of the primary author's academic setting and the involved healthcare system approved the study prior to its inception. With enthusiastic support of the clinic administration, the primary author recruited participants through a personal letter sent to each clinic provider. The letter described the goals of the study and encouraged staff participation in one of three scheduled focus groups over a three-month period.

Prior to each focus group, study participants provided demographic data and gave informed consent for the session to be audio taped and digitally recorded before discussion. An experienced moderator used an interview guide with broad and open-ended questions addressing the research study question (see Figure 1). Use of additional interview probes helped clarify participant responses. Double taping of groups captured accurate data for typed transcripts. Participants received assurance that their comments would be kept confidential. Researchers requested participants to not share group discussion with other staff to allow new perspectives from each group. Research team members included the authors, a moderator with social work background, and a Mexican American bilingual researcher.

Each focus group occurred in a private conference room with participants arranged around a large oval table. Based on research team data analysis after each session, questions varied slightly during subsequent focus groups. The variations captured the essence of participant responses, clarified them, and allowed data saturation to occur. Notes were taken to document contextual aspects of each focus group. The research team provided healthy breakfast foods before the clinic opened for each session held. The focus groups lasted from 60–90 minutes. Each participant received a \$25 gift certificate at the end of their focus group.

Data Analysis

Each audiotape and digital recording was transcribed and the written transcript accurately reflected both versions. Data analysis occurred through a sequential process described by Glaser (1992). Each team member, diverse in scientific, clinical expertise, and ethnic background, independently reviewed each transcription and contextual notes. Credibility, auditability, and dependability measures of trustworthiness in qualitative studies

Meaning of Cancer

1. How do Mexican American female caregivers respond to a diagnosis of cancer in a family member?

Probes:

- How is this response different from that of an African American female caregiver or a caregiver of a different ethnicity?
- What factors may cause a response to cancer based on one's ethnicity and, in particular, Mexican American or Mexican ethnicity?

2. How do Mexican American female caregivers "deal with" a cancer diagnosis and the resulting treatment process?

Probe:

- How does this response vary during the cancer treatment (from initial diagnosis to recovery)?

Learning Needs Related to the Meaning of Cancer

1. How do values, beliefs, and life experiences of Mexican American female caregivers affect their learning needs with cancer?

2. What specific things (ideas, activities, etc.) do Mexican American female caregivers need to learn to effectively care for their ill family member?

3. What barriers exist in the current health delivery system, including the clinic environment, that block the learning needs of Mexican American female caregivers?

Figure 1. Interview Guide

were enhanced by iterative stages of transcription and context note analysis by each team member and then by consensus development of common themes addressed by providers in all focus groups (Bryan et al., 2008; Streubert-Speziale & Carpenter, 2007). Further efforts to ensure credibility of data included having all team members present with data collection and analysis and having providers review their focus group transcript for accuracy (Streubert-Speziale & Carpenter). Participants offered no revisions to the three transcripts.

Results

Participant Characteristics

Twenty healthcare providers (44% of clinic personnel) participated in one of the three focus groups. Providers varied in age, ethnicity, level of education, clinic role, and length of clinic employment (see Table 1). Most providers were of African American or Mexican heritage and were certified nurse assistants, licensed vocational nurses, or receptionists. Most participants reported the need to seek the assistance of others to communicate with Spanish-speaking patients and caregivers.

Themes

Based on provider perceptions of the meaning of cancer to Mexican American family caregivers, five themes emerged from the transcripts: Caregivers fear the cancer diagnosis, interpret cancer as punishment, value maintenance of hope, selectively disclose medical information to the patient and other family members, and believe in God and the doctor.

Table 1. Participant Characteristics

Characteristic	n	%
Age (years)		
Range = 24–54	–	–
\bar{X} = 40.9	–	–
Marital status		
Married	11	55
Separated or divorced	3	15
Single	6	30
Ethnicity		
Non-Hispanic Caucasian	1	5
African American or Mexican descent	15	75
Asian American or Asian descent	2	10
Persian	2	10
Level of education completed		
High school or less	4	20
Some college	10	50
College or graduate degree	6	30
Role at clinic^a		
RN	2	10
Licensed vocational nurse	3	15
Certified nursing assistant	3	15
Doctor	1	5
Social worker	1	5
Administrative assistant	1	5
Receptionist	5	25
Certified pharmacy technician	1	5
Laboratory technician	1	5
Data analyst	1	5
Length of time working at clinic		
Less than 1 year	2	10
1–6 years	7	35
7 years or more	11	55
Length of time having experience with Mexican American caregivers		
1–3 years	4	20
4–6 years	5	25
7 years or more	11	55
Spanish-speaking ability to provide patient care		
Yes	8	40
No	12	60
How non-Spanish speakers communicated needs of Spanish-speaking patients		
Seek translator for help	3	25
Ask Spanish-speaking staff for help	1	8
Ask Spanish-speaking family member of the patient	1	8
Did not respond	7	58

N = 20

^aOne participant did not respond.

Note. Because of rounding, not all percentages total 100.

Fear the cancer diagnosis: Most providers perceived Mexican American family caregivers as fearing diagnosis of cancer more than any other diagnosis because of the belief that their loved one would die. Providers indicated that caregivers demonstrated the fatalistic attitude when they wanted to know at the first clinic visit how many months their loved one had left to live. Providers supported the common cultural belief among Mexican Americans, particularly those with low acculturation status, that cancer is fatal and is “God’s will.”

During the patient’s first visit, the doctor tells the patient and/or family caregiver a lot of things and the information doesn’t soak in because once you say, “You’ve got cancer,” the flaps kind of come down and you just have a blank stare for a while until they can process all of this . . . they are thinking death, because people are like, “I’ve got cancer, and I’m going to die.”

Interpret cancer as punishment: Providers noted that the strong religious orientation of Mexican Americans supports caregivers’ belief that disease, particularly cancer, may occur because a loved one has misbehaved previously. Patients with cancer also may believe this and feel ashamed, which causes feelings of uncertainty in family caregivers about how to address their ill loved one’s needs.

Cancer is a dirty word . . . you are a bad person if you get cancer because God has given you that disease because . . . you are sinful . . . you talk about people, you have affairs . . . you are just a bad person if you get cancer.

In fact, providers perceived that family caregivers did not want to fully disclose the actual cancer diagnosis to an ill loved one because of patient perception that God would no longer love the patient. Likewise, providers perceived family caregivers to believe that if the patient had been a good person, then he or she would not have gotten cancer.

Value maintenance of hope: Many healthcare providers indicated that Mexican American caregivers found accepting the reality of the cancer diagnosis that made a loved one so sick very hard. Providers accepted that the caregivers often denied cancer in a loved one (e.g., he or she “is just sick”) to salvage more hope for the patient, themselves, and the family, despite a common Mexican American perception that the disease is fatal and represents God’s punishment for a past transgression of the afflicted person. In addition, providers noted that family caregivers believed their loved one’s health would not worsen if they did not talk about the cancer. Acknowledging the cancer and losing hope might cause the patient to give up in all aspects of life, including refusal to participate in family activities—a core value in Mexican American culture. Hope also is a value of Mexican American culture, as confirmed by providers: “Hope dies last of all” (Sellers, 1994, p. 71).

Right up to the end, the family caregiver thinks that God will come and save the patient. If [a provider] tells the caregiver that the patient has six months to live, then the caregiver won’t tell the patient that he or she has six months to live, because the caregiver doesn’t want the patient to suffer and get depressed or anything . . . but the caregiver still holds on till the very end, till the patient takes their last breath that God is going to take the cancer away.

Selectively disclose medical information: Many health-care providers indicated that Mexican American family caregivers worked very hard to keep the actual diagnosis of cancer from their ill loved one. For example, one provider noted that a caregiver wanted the doctor to tell the patient he had a tumor rather than cancer, perhaps as a way for the patient to maintain face within his or her family and community and experience less shame. Several providers described instances when the family member(s) of the patient would privately approach the providers and plead with them not to tell the ill family member the actual cancer diagnosis.

Well, I have seen it in cases . . . where caregivers will pull you outside the door . . . and they will come up and say, "Don't tell [the patient] that he has metastatic cancer . . . we don't want him to know, we don't want to put him through more depression."

In addition, several providers described instances when the family caregivers would "sometimes omit something" regarding the diagnosis, perhaps to protect the patient from feeling they had been bad in God's eyes. The providers accepted that the family would do this because the caregiver knows the patient more than anyone and advocates for his or her best interests. The approach also allowed the patient to maintain a firm belief in God and strong family connections, important Mexican American values.

Believe in God and the doctor: Healthcare providers perceived that Mexican American family caregivers place all of their trust and hope in God and the doctor (as an extension of God) who will "take away" the cancer, which might be the reason caregivers seek to hide the actual diagnosis from the patient. The family caregiver and family are able to remain hopeful, faithful, and respectful of the saving powers of God and the doctor with the approach.

Mexican Americans think God is going to take care of everything . . . and then the second God is the doctor—whatever God doesn't fix, the doctor will fix.

However, providers noted frustration in dealing with caregivers who firmly believed that the doctor's interventions would save the patient because they were divine in origin and not to be questioned. Providers recounted frustration in getting these patients and family caregivers to call the clinic when doctor-prescribed patient medications were ineffective for a patient's pain or treatment side effects. Providers perceived that Mexican American caregivers did not report the lack of effectiveness because they believed it disrespected the doctor who is connected to God.

Interpretation

The current study involving providers of cancer care and the earlier grounded theory study with Mexican

American caregivers (Wells et al., 2008) show similar findings related to the meaning of cancer to caregivers and its influence on their learning and support needs. Both studies supported caregiver fear of the cancer diagnosis, belief in God and the doctor, and the value of hope in coping with cancer. However, caregivers in the grounded theory study did not identify two provider themes: cancer as punishment and selective disclosure of medical information. Perhaps caregivers did not feel comfortable addressing such beliefs with college-age female Mexican American research assistants who collected data twice in the grounded theory study. Caregivers voiced a close relationship with providers over a lengthy period of cancer treatment. That trust may have supported caregiver sharing of cancer as punishment and nondisclosure or selective disclosure of medical information, particularly when staff nurtured caregiver belief that such disclosure was acceptable to maintain patient and family hope (Ayalon, 2004; Frank et al., 2002; Juarez, 2003).

Overall, themes found in both studies support partnering of providers, including nurses and caregivers, to meet the latter's needs for learning and support based on both groups' perceptions of cancer's cultural meaning to caregivers. Caregivers voiced trust in clinic staff, particularly the doctor, based on staff openness to dialogue and support during patient visits (Wells et al., 2008). The trust may have been further nurtured by the clinic's willingness to provide care when no other agency stepped forward to do so, particularly in cases of undocumented patient status. However, following interview probes, caregivers identified an urgent need to learn more about the cancer diagnosis, treatment effects, and ways to respond to patient pain, nutrition, and medication issues (Wells et al.). Providers agreed that routine assessment of caregiver learning style and use of their "voices" to tailor culturally relevant teaching, support, and modeling of patient care skills could meet caregiver desire for essential knowledge and skill acquisition to continue caregiving (Barrett et al., 2008).

Themes identified in both studies support the priority need for cancer care agencies to focus on health literacy issues of those they serve. The Institute of Medicine (IOM, 2004) defines health literacy as the ability to read, understand, and appropriately act on health information. With almost 10% of the U.S. population lacking English language proficiency, and most of that group speaking Spanish (Shin & Bruno, 2003), health literacy, including that of Mexican American caregivers, remains a problem. Providers noted absent or limited Spanish caregiver learning materials (e.g., pamphlets, videos, computers) in the clinic. Those that were available were at high literacy levels. With limited educational resources, few staff to translate cancer materials into Spanish, and few healthcare personnel trained at the professional nursing level (bachelor of science in nursing) to deliver effective patient teaching, caregivers may have believed that their

loved one with cancer will die, cancer is God's punishment, God delegates the doctor to help their loved one, and one cannot lose hope in the situation. Selective disclosure may allow caregivers to control the cancer situation when so much of the cancer scenario seems to be out of control, uncertain, and not well understood.

Caregiver and provider studies identified that Mexican American family caregivers had limited education and English-speaking ability and that the clinic needed more social workers, space, and private talking areas to address learning and continuity of care issues for Mexican American families experiencing cancer. Caregiver and provider voices (Leininger & McFarland, 2002) could define needed physical, emotional and spiritual, and social support resources to improve caregiver understanding of cancer and ways to effectively respond to caregiver and patient needs at different points in the cancer trajectory (Coward & Kahn, 2004; Overcash, 2004; Sorensen, Pinquart, & Duberstein, 2002). Although time, financial, and clinic structural issues (Sakalys, 2003; Santoso et al., 2006) may prevent implementation and evaluation of health literacy programs (Barrett et al., 2008), studies document that individuals with limited literacy and English proficiency misunderstand treatment recommendations and practice less preventative health care, contributing to high social healthcare costs (Agency for Healthcare Research and Quality, 2004; Baker et al., 2007; IOM, 2004). Provider and caregiver partnering with Spanish-speaking community healthcare workers may inform changes to agency structure and process of care. The changes could support greater caregiver and patient understanding of treatment recommendations and provision of needed caregiver preventative health care and teaching during patient clinic visits (Hubbell, 2006).

Conclusions

Although the provider study had some limitations, blending voices of Mexican American family caregivers and healthcare providers offers an opportunity for greater understanding of cancer meaning to caregivers to define appropriate interventions to meet their support and learning needs. The sample was small, limiting the research team's ability to generalize findings to a larger group of cancer clinic providers. Data collection occurred only in morning sessions because of clinic operations, which may have prevented broader and more provider participation, including more doctors and RNs. Most participants did not speak Spanish and held nondegree professional roles that perhaps limited their scope of practice to address the diverse and complex needs of Mexican American caregivers. The phenomenon of social loafing, lack of participant involvement because of lack of trust or need to conform to others' opinions within the focus group (Thackeray & Neiger, 2004), also may have operated in two of the largest focus

- Evaluation of efficacy of community healthcare workers ("La Promotoras") as members of healthcare provider teams to address cost, access, and quality issues for meeting, learning, support, and overall health promotion of Mexican American caregivers and families
- Exploration of spiritual and social support resources used by Mexican American caregivers during cancer trajectory based on identified themes of cancer meaning; exploration of use, variation, and efficacy of the resources for caregivers during phases of the cancer cycle; exploration of caregiver acceptance of spiritual care by providers who perceive caregiver burden
- Exploration of influence of caregiver acculturation level on meaning of cancer and identified themes of provider study; identification of relevant healthcare resources, learning materials based on literacy, and effective provider-caregiver partnering models to meet needs of caregivers of various acculturation and learning levels
- Examination of Mexican American acceptance of social support agency help during cancer cycle because of belief that caregiving is an obligatory role for Mexican American women and family "cares best for the patient"
- Measurement of the effect of Spanish language support groups taught by a team of clinic providers using information from Mexican American caregivers to improve caregiver health promotion behaviors and learning and to address caregiver uncertainty with cancer diagnosis
- Development of tailored and culturally sensitive health promotion interventions (Smedley, Stith, & Nelson, 2002) for Mexican American caregivers and families during the cancer experience
- Development and evaluation of effective academic community clinic team partnerships (informed by caregiver knowledge, beliefs, and learning needs) to meet student learning needs and effective care of Mexican American families experiencing cancer
- Evaluation of partnerships between pharmaceutical companies, healthcare agencies, professional associations (Oncology Nursing Society, American Public Health Association), or local healthcare agencies to produce cost-effective and appropriate learning materials to meet needs of Mexican American families during the cancer cycle
- Examination of effective clinic structure and space models that address oral tradition of Mexican American caregivers for peer and one-on-one learning of knowledge and skill development for quality patient cancer care
- Development and evaluation of staffing models (professional nurses, physicians, certified nursing assistants, social workers, community health workers) to address diverse learning, teaching, and support needs of Mexican American families experiencing cancer

Figure 2. Areas for Further Research to Improve Learning and Support Needs of Mexican American Cancer Caregivers

groups, which could have affected quality and quantity of data from the study.

This study offers insight into other areas of research to support learning and needs of Mexican American cancer caregivers (see Figure 2). Such research must explore effective partnership models among caregivers, healthcare team members of diverse preparation and disciplines, and agencies who focus on improving

healthcare outcomes for Mexican American caregivers and those for whom they care. Further work also must occur to use caregiver and provider beliefs about cancer to develop and evaluate the efficacy of care environments and learning materials for Mexican American caregivers and families with low literacy or limited English ability. The materials will meet learning and support needs of family caregivers and enable them to “become stronger” during the care cycle to continue their role as caregivers.

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References

- Agency for Healthcare Research and Quality. (2004). *Literacy and health outcomes: Evidence report/technology assessment No. 87* (AHRQ Publication No. 04-E00072). Washington, DC: U.S. Government Printing Office.
- Allison, K.G., Duran, M., & Pena-Purcell, N. (2005). Cervical cancer screening practices among Hispanic women: Theories for culturally appropriate interventions. *Hispanic Health Care International*, 3(2), 61–67.
- Ashing-Giwa, K.T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A. et al. (2004). Understanding the breast cancer experience of women: A qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-Oncology*, 13(6), 408–428.
- Ayalong, L. (2004). Cultural variants of caregiving or the culture of caregiving. *Journal of Cultural Diversity*, 11(4), 131–138.
- Baker, D.W., Wolf, M.S., Feinglass, J., Thompson, J.A., Gazmararian, J.A., & Huang, J. (2007). Health literacy and mortality among elderly persons. *Archives of Internal Medicine*, 167(14), 1503–1509.
- Barrett, S.E., Puryear, J.S., & Westpheling, K. (2008). *Health literacy practices in primary care settings: Examples from the field*. Retrieved January 31, 2008, from <http://www.commonwealthfund.org>
- Berg, J.A., Cromwell, S.L., & Arnett, M. (2002). Physical activity: Perspectives of Mexican American and Anglo American midlife women. *Health Care for Women International*, 23(8), 894–904.
- Borrayo, E.A., Laws, C., & Coit, C. (2005). Latinas’ appraisal of participation in breast cancer prevention clinical trials. *Cancer Control*, 12(Suppl. 2), 107–110.
- Bryan, C.J., Wetmore-Arkader, L., Calvano, T., Deatricks, J.A., Giri, V.N., & Bruner, D.W. (2008). Using focus groups to adapt ethnically appropriate, information-seeking, and recruitment messages for a prostate cancer screening program for men at high risk. *Journal of the National Medical Association*, 100(6), 674–684.
- Cagle, C.S., Wells, J.N., Hollen, M.L., & Bradley, P. (2007). Weaving theory and literature for understanding Mexican American cancer caregiving. *Hispanic Health Care International*, 5(4), 149–161.
- Carter, P.A. (2006). A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nursing*, 29(2), 95–103.
- Coward, D.D., & Kahn, D.L. (2004). Resolution of spiritual disequilibrium by women newly diagnosed with breast cancer. *Oncology Nursing Forum*, 31(2), E24–E31.
- Crist, J.D., Garcia-Smith, D., & Phillips, L.R. (2006). Accommodating the stranger en casa: How Mexican American elders and caregivers use formal care. *Research and Theory in Nursing Practice*, 20(2), 109–206.
- Fernandez, M.E., Palmer, R.C., & Leong-Wu, C.A. (2005). Repeat mammography screening among low-income and minority women: A qualitative study. *Cancer Control*, 12(Suppl. 2), 77–83.
- Frank, G., Blackwell, L.J., Murphy, S.T., Michel, V., Azen, S.P., Preloran, H.M., et al. (2002). Ambiguity and hope: Disclosure preferences of less acculturated elderly Mexican Americans concerning terminal care—A case story. *Cambridge Quarterly of Healthcare Ethics*, 11(2), 117–126.
- Glaser, B.G. (1992). *Basics of grounded theory analysis: Emergence vs. forcing*. Mill Valley, CA: Sociology Press.
- Gordon, L. (2004). Facing racial and ethnic health disparities. *Journal of the American Dietetic Association*, 104(12), 1779–1780.
- Hamner, T.J., & Turner, P.H. (1996). *Parenting in a contemporary society* (3rd ed.). Boston: Allyn and Bacon.
- Hubbell, A.P. (2006). Mexican American women in a rural area and barriers to their ability to enact protective behaviors against breast cancer. *Health Communication*, 20(1), 35–44.
- Institute of Medicine. (2004). *Health literacy: A prescription to end confusion*. Washington, DC: National Academies Press.
- Jolicoeur, P.M., & Madden, T. (2002). The good daughters: Acculturation and caregiving among Mexican-American women. *Journal of Aging Studies*, 16(2), 107–120.
- Juarez, G. (2003). *Perceptions of the caregiving experience and quality of life: Mexican/Mexican American caregivers providing care to adults with advanced cancer*. Unpublished doctoral dissertation: University of California at Los Angeles.
- Juarez, G., Ferrell, B., & Borneman, T. (1998). Perceptions of quality of life in Hispanic patients with cancer. *Cancer Practice*, 6(6), 318–324.
- Kline, M.V. (1999). Planning health promotion and disease prevention programs in multicultural populations. In R.M. Huff & M.V. Kline (Eds.), *Promoting health in multicultural populations: A handbook for practitioners* (pp. 73–102). Thousand Oaks, CA: Sage.
- Leininger, M., & McFarland, M.R. (2002). *Transcultural nursing: Concepts, theories, research, and practice* (3rd ed.). New York: McGraw Hill.
- Matthews, B.A. (2003). Role and gender differences in cancer-related distress: A comparison of survivor and caregiver self-report. *Oncology Nursing Forum*, 30(3), 493–499.
- Mendelson, C. (2002). Health perceptions of Mexican American women. *Journal of Transcultural Nursing*, 13(3), 210–217.
- Moore, M.J., Moire, P., & Patrick, M.M. (2004). *The state of aging and health in America 2004*. Retrieved February 5, 2007, from http://www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf
- Northouse, L., Kershaw, T., Mood, D., & Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psycho-Oncology*, 14(6), 478–491.
- Northouse, L., Templin, T., & Mood, D. (2001). Couples’ adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine*, 24(2), 115–136.
- Northouse, L.L., Walker, J., Schafenacker, A., Moody, D., Mellon, S., Galvin, E., et al. (2002). A family-based program of care for women with recurrent breast cancer and their family members. *Oncology Nursing Forum*, 29(10), 1411–1419.
- Overcash, J.A. (2004). Using narrative research to understand the quality of life of older women with breast cancer. *Oncology Nursing Forum*, 31(6), 1153–1159.
- Phillips, L.R., Torres de Ardon, E., Komnenich, P., Killeen, M., &

- Rusinak, R. (2000). The Mexican American caregiving experience. *Hispanic Journal of Behavioral Sciences*, 22(3), 296–313.
- Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregivers: A meta-analysis. *Gerontologist*, 45(1), 90–106.
- Sabogal, F., Marin, G., & Otero-Sabogal, R. (1987). Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Sciences*, 9(4), 397–412.
- Sakalys, J.A. (2003). Restoring the patient's voice. The therapeutics of illness narratives. *Journal of Holistic Nursing*, 21(3), 228–241.
- Santoso, J.T., Engle, D.B., Schaffer, L., & Wan, J.Y. (2006). Cancer diagnosis and treatment: Communication accuracy between patients and their physicians. *Cancer Journal*, 12(1), 73–76.
- Schettino, M.R., Hernandez-Valero, M.A., Moguel, R., Hajek, R.A., & Jones, L.A. (2006). Assessing breast cancer knowledge, beliefs, and misconceptions among Latinos in Houston, TX. *Journal of Cancer Education*, 21(1), S42–S46.
- Sellers, J.M. (1994). *Folk wisdom of Mexico*. San Francisco: Chronicle Books.
- Shah, M., Coyle, Y., Kavanaugh, A., Adams-Hult, B., & Lipsky, P.E. (2004). Focus group assessment of culturally specific cholesterol-lowering menus for Mexican Americans. *International Electronic Journal of Health Education*, 1(7), 9–19.
- Sheldon, L.K. (2005). Communication in oncology care: The effectiveness of skills training workshops for healthcare providers. *Clinical Journal of Oncology Nursing*, 9(3), 305–312.
- Shin, H.B., & Bruno, R. (2003). *Language use and English-speaking ability: 2000*. Washington, DC: U.S. Census Bureau.
- Smedley, B.D., Stith, A.Y., & Nelson, A.R. (2002). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academy Press.
- Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist*, 42(3), 356–372.
- Streubert-Speziale, H.J., & Carpenter, D.R. (2007). *Qualitative research in nursing: Advancing the humanistic imperative*. Philadelphia: Lippincott Williams and Wilkins.
- Swore Fletcher, B.A., Dodd, M.J., Schumacher, K.L., & Miaskowski, C. (2008). Symptom experience of family caregivers of patients with cancer [Online exclusive]. *Oncology Nursing Forum*, 35(2), E23–E44. Retrieved July 22, 2009, from <http://ons.metapress.com/content/m0v8m3135m84q864/fulltext.pdf>
- Thackeray, R., & Neiger, B.L. (2004). Misconceptions of focus groups: Implications for health education practice. *American Journal of Health Education*, 35(4), 214–219.
- 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.
- Wells, J.N., Cagle, C.S., & Bradley, P.J. (2006). Building on Mexican American cultural values. *Nursing*, 36(7), 20–21.

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Listen as *Oncology Nursing Forum* Associate Editor Ellen Giarelli, EdD, RN, CRNP, interviews Carolyn Spence Cagle, PhD, RNC, about cultural beliefs counterproductive to patient care and optimizing staffing models to improve culturally sensitive health care. Cagle is an associate professor of nursing in the Harris College of Nursing and Health Sciences at Texas Christian University in Fort Worth and currently receives funding from the ONS Foundation to study spirituality among Mexican American cancer caregivers.

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