Culturally Sensitive Care

Enlisting community partners to meet Mexican American caregiver needs

Carolyn Spence Cagle, PhD, RNC-OB, and Jo Nell Wells, PhD, RN, OCN

BACKGROUND: Culturally sensitive interventions are needed to assist Mexican American (MA) patients with cancer and their family members in managing their care, navigating the healthcare system, and decreasing disparities in healthcare outcomes for Hispanics with cancer.

OBJECTIVES: The objectives of this study were to understand the meaning of culturally sensitive care for oncology clinic healthcare providers and to assess the usefulness and feasibility of the role of a promotora de salud to meet caregiver needs.

METHODS: This study involved focus groups of 18 diverse providers who provided data for qualitative analyses.

FINDINGS: The findings (themes) defined the facilitators of and barriers to culturally sensitive care and the perceived role of a promotora de salud to support the healthcare team and improve cancer care provided by MA caregivers. In addition, promotoras de salud can help reduce health costs by decreasing patient clinic visits.

IN 2012, HISPANICS IN THE UNITED STATES DIED MORE OFTEN from cancer than non-Hispanic Caucasians, who died more often from heart disease (American Cancer Society [ACS], 2015; Colby & Ortman, 2014; Siegel, Fedewa, et al., 2015). Although Hispanic lung cancer rates and deaths are 50% lower than those of African Americans, 17% of Hispanic males die from lung cancer. Hispanic women also experience higher rates of cervical and gallbladder cancer compared to non-Hispanic Caucasians (ACS, 2015). On the other hand, Hispanic women experience lower rates of breast cancer (16%) but have later stages of diagnoses, contributing to higher death rates from this disease (ACS, 2015; Juarez, Hurria, Uman, & Ferrell, 2012). Immigrant Hispanic women face later stages of breast cancer at diagnosis, and premenopausal Mexican women have a higher risk for developing breast cancer earlier in life than women of other ethnic groups (Keegan, Quach, Shema, Glaser, & Gomez, 2010; Miranda et al., 2011).

Research indicates that factors contributing to disparate cancer rates and deaths in Hispanic populations include low access to health care, low education and literacy levels, limited English proficiency, and limited financial and network resources (National Cancer Institute [NCI], 2016]. Higher rates of obesity among Hispanics increase cancer risk, as do other lifestyle factors, such as lack of a healthy diet and exercise and greater environmental exposure to infectious agents (ACS, 2015; Centers for Disease Control and Prevention [CDC], 2016; NCI, 2016; Palos et al., 2010).

Mexican Americans (MAs) are the largest subgroup of Hispanics in the United States (64%) (ACS, 2015). Healthcare providers must address the healthcare disparities and needs of MAs, who are a rapidly growing minority population (Alicea-Planas, 2013). Culturally sensitive interventions to assist MA patients with cancer and their family caregivers to self-manage and navigate the healthcare system are integral to decreasing health disparities that influence early Hispanic death, social and economic loss, and lower quality of life for affected people and MA communities (CDC, 2016; Doornbos, Ayoola, Topp, & Zandee, 2015; Ingram, Sabo, Rotherstrom, & de Zapien, 2008; Juarez, Branin, & Rosales, 2014; NCI, 2016; Palos et al., 2010).

Background

Most MA cancer care occurs in the home because many MAs lack healthcare access and also have strong cultural values related to familial duty and

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parental respect (Crist, Garcia-Smith, & Phillips, 2006; Juarez et al., 2014; Phillips, de Ardon, Kommenich, Killeen, & Rusinak, 2000). However, research indicates that MA family cancer caregivers (MAFCGs) have unmet learning needs that affect their ability to provide home care for ill family members. MAFCGs want to learn more about cancer; how to provide care; and strategies to communicate with doctors, ill family members, and other family members (Juarez et al., 2014; Palos et al., 2010; Wells, Cagle, Bradley, & Barnes, 2008; Wells, Cagle, Marshall, & Hollen, 2009). Unmet caregiver learning needs create role-related stress that negatively influences caregiver and patient health and contribute to caregiver burden (Brooks, 2016; Northouse, Katapodi, Song, Zhang, & Mood, 2010; Palos et al., 2010; Tipton, Coe, Matthews, & Mitchell, 2016). These unmet learning needs also increase the risk of caregiver mortality (Fowler, 2014).

MAFCGs and cancer-clinic care providers may have different beliefs and values related to patient disease disclosure and acceptance, pain assessment and interventions, and asking questions to “godlike” doctors (Cagle & Wells, 2010; Cagle & Wolff, 2009). These disparate values and beliefs may contribute to staff, patient, and caregiver misconceptions about needed care components (e.g., culturally sensitive education, resource support, emotional interventions) (Cagle & Wells, 2010; Cagle & Wolff, 2009; McDonald, Ambrose, & Morey, 2014; Phillips & Crist, 2008). One theory supports that MAFCGs, although burdened in this role, are strengthened by caregiving and perceived support from cancer care teams (Wells et al., 2008, 2009).

A number of studies have identified the positive impact of a promotora de salud (PdeS), or a Latina promoter of health, as a member of the healthcare team on MA patient and family healthcare outcomes (Fernández et al., 2009; Godecker, Harrison, & Sidebottom, 2013; Rhodes, Foley, Zometa, & Bloom, 2007; Waitzkin et al., 2010; WestRasmus, Pineda-Reyes, Tamez, & Westfall, 2012). A PdeS is a lay MA trained by the state as a certified community health worker. Trained researchers or clinic staff, including nurses, work with PdeSs to help them fill health promotion roles of care for a particular illness population (e.g., diabetics) in a certain employment setting (WestRasmus et al., 2012). PdeSs work with healthcare providers in the clinic to address care processes and literacy issues that may affect cost, access, and healthcare quality in diverse population groups (Cupertino et al., 2014; Hargraves, Ferguson, LeMay, & Pernice, 2012; WestRasmus et al., 2012). Educated in cancer illness care, PdeSs may serve as an ethnically congruent helper to MAFCGs and their families to provide culturally sensitive care. They understand the traditional Hispanic cultural beliefs related to cancer, such as the belief that cancer is fatal, and the importance of Hispanic cultural values of respect and personal connection. PdeS care supports MAFCGs and helps them cope with the “tricky disease” of cancer (Kennedy, 2005; Luckett et al., 2011; Wells et al., 2009).

Evidence suggests that PdeS-delivered care supports improvements in Hispanic health status, migrant Latina cancer screening, emergency department use, and diet and medication adherence in chronic illness (Babamoto et al., 2006; Fernández et al., 2009; Larkey et al., 2012; Lujan, Ostwald, & Ortiz, 2007). The presence of a PdeS has also decreased pregnancy health costs associated with psychosocial issues, such as lack of housing and social support and increased rates of depression, among Hispanic women (Godecker et al., 2013). Despite these successes, limited descriptive research has been conducted on the use of PdeSs in cancer settings or with MA cancer caregivers. The purpose of this pilot study was to understand provider perceptions of incorporating PdeSs as clinical partners in public cancer clinics and to use that information to shape a feasible role for PdeSs to respond to the identified needs of MAFCGs.

Methods

The research team consisted of two nursing faculty researchers, one Hispanic undergraduate research assistant, and a PhD-prepared, bilingual/bicultural MA consultant with expertise in PdeS training programs. In a descriptive study design, researchers used a focus group methodology and theoretical sampling to gather knowledge from individuals directly experiencing a phenomenon (an experience of defining the “fit” of a PdeS as a member of the cancer clinic team) to create meaning from that experience (Munhall, 2012).

Sample

The study sample (N = 18) included cancer clinic employees from John Peter Smith Health Network in Fort Worth, Texas, who participated in one of three focus groups with five to eight participants in each group. The groups were composed to support meaningful participant conversation to meet the study aim (Speziale, 2003a). Snowball sampling (study participants encouraged friends to participate if they met study inclusion criteria) between groups allowed sample maximum variation (Patton, 1990) by role (e.g., doctor, nurse) and other characteristics (e.g., age, length of employment). About half the clinic employees met the inclusion criteria—including the ability to speak English, a willingness to engage in one of three focus groups, and employment in a direct cancer care role (RN, social worker, certified nurse assistant, licensed vocational nurse, interpreter, radiology technician, administrative assistant, clinic educator) for MA patients and their families. The sample size met Patton’s (1990) criteria of “what researchers wanted to know, what was at stake, what would be useful, what would have credibility, and what could be done with available time and resources” (p. 184). Researchers provided a $30 gift card to each participant to show appreciation for their study participation.

Following approval from the institutional review boards of Texas Christian University and John Peter Smith Health Network,
35–40 employees received email invitations describing the study and requesting their participation. Each employee who provided informed consent participated in one of three groups during a two-month period. Participants attended either a focus group conducted before the clinic opened or one during the lunch hour.

The first author, who had experience facilitating focus groups and knowledge of qualitative methodologies, served as focus group moderator for all sessions. Each session lasted 60–90 minutes and was held in a private clinic conference room. Another member of the research team participated in the focus groups to ensure data reliability and validity of the study process. Double audio recording of each group captured data for transcription and provided assurance against possible equipment failure. A semi-structured interview guide (revised after each group and based on authors’ prior works), pilot testing, and relevant literature guided group discussions (Doody, Slevin, & Taggart, 2013) (see Figure 1).

Group discussions focused on definitions of culturally sensitive care, the sociopolitical environment of MAs with cancer and MAPCG needs, and the staff perceptions of the feasibility of PdeSs as partners in team-based clinic care. After each group meeting, team members composed contextual notes (“What happened beyond group words?”) and reflective notes (“How do the data connect and influence study purpose?”) to aid in later data analysis (Speziale, 2003b). Data saturation had occurred by the third focus group (researchers heard repetition and confirmation of earlier focus group information), meeting the study purpose and initiating the cessation of study recruitment.

Analyses
Data analysis occurred through a sequential process involving the review of audio-recorded transcriptions within 10 days of each group meeting, connecting text, contextual and reflective notes, and clusters of similar data (Speziale, 2003b), and listing themes and patterns specific to each interview guide question (Doody et al., 2013). Analysis phases involved in-depth “reading, intuiting, cyclical questioning and verifying, analyzing, synthesizing, and reporting discoveries” (Speziale, 2003b, p. 36). The analysis process was focused on ensuring data reliability and validity (credibility, confirmability, and dependability) (Kidd & Parshall, 2000; Speziale, 2003b) during individual team member analysis and group analysis. Data summary occurred in aggregate form found in many descriptive qualitative study reports.

Results

Sample
Of the 18 participants, five were RNs, four were social workers or certified nurse assistants, and fewer than three were licensed vocational nurses, interpreters, or radiology technicians. More than six served as administrative assistants or clinic educators. Of the sample, six identified as African American and four as Hispanic. The remaining participants identified as non-Hispanic Caucasian or Asian. Study themes revealed in the study were the facilitators of and barriers to provider definitions of culturally sensitive care and the perceived role of PdeSs to meet clinic goals and improve cancer care provided by MAPCGs.

Culturally Sensitive Care
The initial interview guide question sought participant perceptions of culturally sensitive care and related workplace examples. The moderator further queried the participants about barriers and facilitators of that care in the clinic.

PERCEPTIONS AND EXAMPLES
Participants described culturally sensitive care as respectful, responsive, resource-connecting, and focused on relationship establishment among patients, healthcare providers, and caregivers. Culturally sensitive care adapts to individual patient needs, beliefs, and behaviors, and aligns with patient and family choices. Participants believed that this approach does the “most good” for the patients’ overall health and family well-being. Culturally sensitive care is “treatment of the patient and not the cancer, and allows the patient to control the illness and prevent the cancer from controlling the patient.” Overall, culturally sensitive care...
care is holistic care, involving the family of the patient with cancer, because they “deal with this devastating disease, too.”

Participants identified the MAFCG as the “go-to person, the family nurturer, [the] one who holds everything up and together, and always puts [him or herself] last.” Following this insight, participants discussed the clinic’s need to better support and be inclusive of MAFCGs in patient care delivery to minimize stress and provide culturally sensitive care. Providers should encourage caregivers during patient encounters to “take time for [themselves]; this is [their] time to care for self to allow caregiving of the ill patient.”

Participants noted that healthcare providers must encourage caregiver questions during patient clinic visits so that MAFCGs understand cancer and believe that their care matters to the family. Providers may also assist caregivers by connecting them with appropriate providers and traditional ethnic practices to meet cancer care-related needs. Additional care for the caregivers not yet practiced may include the use of prayer, massage, and historical remedies, and provider use of nonverbal behaviors to show support.

FACILITATORS OF CULTURALLY SENSITIVE CARE
Participants reported agency support for culturally sensitive care through administration-mandated training for new employees about diverse cultures, and annual employee evaluations of providing sensitive care to meet the cultural needs of the patients. Participants believed that the hospital network, including the cancer clinic, supported diversity through annual initiatives focused on different ethnic groups and the presence of ethnically diverse individuals and culturally respectful slogans on network buildings.

In addition, participants noted the clinic support of culturally sensitive care through the employment of diverse staff, the use of Spanish educational materials, and the availability of informed consent documents in Spanish and other languages. Social worker participants voiced a commitment to prioritizing patient–provider relationships during cancer treatment to tailor MAFCG care. Participants added that a dedicated staff and the employment of a full-time interpreter and two medical providers who spoke multiple languages showed sensitivity to the needs of Spanish-speaking patients and families, connecting them to needed clinic services.

BARRIERS TO CULTURALLY SENSITIVE CARE
Participants identified the following barriers to culturally sensitive clinic care: (a) language barriers between providers and patients/families, (b) lack of diversity among providers, (c) financial issues preventing access to patient care (“one has to pay to get care started,” “there is not much we can do”), (d) governmental/public health reimbursement for patient visits and cancer procedures, and (e) low literacy of patients/families, which prevents optimal care outcomes. Others noted barriers to MAFCG receipt of cancer information and access to care related to conflicting cultural beliefs, behaviors, and personalities among patients, caregivers, providers, and clinic administrators (e.g., “immigrants believe American health care is free,” “administrators don’t have to tell patients to pay up front”). Participants noted that Health Insurance Portability and Accountability Act (HIPAA) regulations influenced the sharing of patient information within families and with other patients with cancer and their caregivers. The clinic’s ability to fully provide culturally sensitive care was influenced by the limited number of English/Spanish interpreters to help clarify information and increase patient and family coping during cancer. Most study participants believed the following quote defined the reality of providing culturally sensitive care: “Learning and then practicing ways of providing culturally sensitive care for all is a work in progress.”

Recaptivity to and Feasibility of a Clinic Promotora de Salud
The moderator sought participant input about the ways a PdeS (defined as a community health worker) would operate as part of the clinic care team. Only two participants initially recognized the term promotora de salud from past work experience. Once told that PdeSs promote the health of MA communities, participants overwhelmingly agreed that they would be an asset to clinics by providing culturally sensitive care. Many respondents supported a possible clinic role for two or three part-time PdeSs to defer “the toll of so many Spanish-speaking MA families needing support and information.” One clinic social worker believed that a trained PdeS would extend her work, decrease social work burden, and improve patient outcomes and quality of life. In addition, participants spoke about ways to measure the effectiveness of a clinic partnership with PdeSs to tailor care for MA families.
ROLES OF A PROMOTORA DE SALUD
Participants identified that a PdExS could fill a current service gap by leading Spanish-speaking caregiver support groups designed for MAFCGs, scheduling needed child care during patient appointments (“caregivers want to make sure their children are safe”), and connecting caregivers to resources and to one another to “keep the patient and caregiver at the center of care.” Overall, PdExSs would provide support services that would increase caregiver coping and avoid the “deer in the headlights” look that many families get when given a cancer diagnosis of a loved one.

Participants saw value in the presence of a PdExS during the delivery of a cancer diagnosis to a patient and family caregiver but expressed uncertainty about whether her presence would meet current HIPAA regulations and family privacy needs. Other PdExS roles delegated by clinical nursing might include teaching healthy nutrition classes, offering caregiver health promotion of screening and follow-up, and helping caregivers develop organizational skills for scheduling patient appointments. The PdExS could also teach financial classes and help caregivers with personal care issues that affect self-esteem. In addition, a PdExS could help to schedule transportation services for patients and caregivers who often miss appointments.

QUALIFICATIONS OF A PROMOTORA DE SALUD
Participants suggested that a clinic PdExS should have experience as a cancer survivor or cancer caregiver to foster compassion, superb listening skills, and internal spiritual strength to cry and pray with MA families as appropriate, and should live in an MA community to provide an understanding of the caregiver experience and the need for community health promotion activities. Participants believed that a PdExS should be able to develop close, trustworthy caregiver relationships and “to kind of walk hand in hand with caregivers” to help them “become less lost” in complex cancer treatment. The PdExS should also advocate for the “caregiver voice” when a caregiver perceives a doctor as “God” and does not ask questions out of respect. A bilingual PdExS should communicate with the healthcare team on behalf of MAFCGs and patients, encourage mutual understanding of one another’s perspective, and be sensitive to MAFCG loss of personal control with the cultural interpretation of cancer (“cancer causes death”). Study participants noted that the PdExS should know her limits, understand clinic communication protocol, and know when to delegate care decisions to other team members.

Discussion and Nursing Implications
Participants in the three focus groups described both hospital/clinic educational mandates and individual worker approaches that may help PdExSs respond to the need for more culturally sensitive care of ethnic groups, including MAFCGs. Education alone on these matters “is a start” toward delivering culturally sensitive care, but a cancer clinic care team inclusive of PdExSs would provide evidence of their efficacy in a cost-effective community-based model (Cupertino et al., 2014; WestRasmus et al., 2012). Study participants defined culturally sensitive care as similar to that of primary care (complementary, culturally sensitive, consumer-based, and coordinated) (Barthow et al., 2014).

Participants noted that the clinic structure and time constraints blocked their efforts to provide the culturally sensitive care and bilingual language access desired by the staff. Data indicated a limited number of appropriate clinic providers to build provider–caregiver relationships essential to responding to MA family needs. Recurrent barriers to desired culturally sensitive care were language differences between MAFCGs and care providers and MA low literacy that hindered overall learning. Participants identified that a PdExS, based on training, experience, and community commitment, could...
address these barriers by partnering with nurses to provide culturally sensitive education, support, and self-confidence to MAFCGs (Medina, Balcazar, Hollen, Nkholma, & Mas, 2007; Urrutia-Rojas & Luna-Hollen, 2012; Wells et al., 2008) (see Figure 2).

Inclusion of PdeSs in cancer care for MAFCGs seems appropriate based on the history of community health workers in the Hispanic community and their collaboration with nurses. The literature describes PdeS success in patient advocacy, patient navigation, and social support consistent with MAFCG noncancer needs (Fischer, Sauaia, & Kutner, 2007; Godecker et al., 2013). PdeSs greatly benefit diverse populations by sharing similar ethnic characteristics, language, residences, and life experiences that support culturally competent care (Godecker et al., 2013; Weber, Sulstarova, & Singy, 2016). These characteristics promote increased cancer and other health screenings and the potential for more Latina involvement in cancer clinical trials to address healthcare disparities in this group (ACS, 2015; Cupertino et al., 2014; Larkey et al., 2012; Rubin, 2014).

Evidence supports that a PdeS can effectively address caregiver psychological needs to reduce the burden of nurses and social workers and decrease caregiver healthcare costs (Fischer et al., 2007; Godecker et al., 2013). PdeSs reduce health costs by decreasing the number of patient clinic visits, care time, transportation costs, MA patient and caregiver hospital or emergency department visits related to medication errors, poor diet, or inability to follow medical advice (Kao & Lynn, 2009; Williams, Lantican, Bader, & Lerma, 2014). Qualitative and quantitative evaluation of these outcomes could refine a PdeS role to meet local cancer care needs, identify and provide needed staff training, and support PdeSs and clinic employees (Alvillar, Quinlan, Rush, & Dudley, 2011; Anders, Balcazar, & Paez, 2006; Fischer et al., 2007). MAFCGs may also provide pre- and post-test assessment of perceived support and content learning from PdeSs. Researchers should periodically assess the success of the PdeS role to support self-evaluation, power sharing, peer training and support, and sustainable best practice success in employment settings (Alvillar et al., 2011; Ayala, Vaz, Earp, Elder, & Cherrington, 2010; Waitzkin et al., 2010).

Limitations

The single qualitative methodological approach, using feedback from 18 healthcare providers, prevents the generalizability of pilot study findings to unlike groups and settings. However, clinic staff members provided information-rich data based on life experience, and study researchers engaged in rigorous data analysis—two factors that have been deemed more significant than sample size (Patton, 1990).

Conclusion

During the focus groups, participant reflections addressed a current literature gap on providers’ definition of cultural-sensitive care and perceptions of the feasibility of employing PdeSs as members of the healthcare team in cancer clinics serving a large number of MAs. This study also provided information responsive to culturally sensitive intervention studies with MAFCGs burdened by cancer illness and few resources to meet role-related needs (Cagle & Wells, 2010; Juarez et al., 2012; Northhouse, 2005; Northhouse et al., 2010). Clinician partnering of a PdeS with a licensed professional (i.e., an RN or a social worker) offers an evidence-based and cost-efficient way of addressing healthcare gaps for MAFCGs (Alvillar et al., 2011; McCloskey, Tollestrup, & Sanders, 2011). Additional studies with larger samples, using data triangulation in different oncology clinic settings, will provide evidence of the value of PdeSs to help meet healthcare goals to improve primary care delivery for underserved MAFCGs.

References


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