Health Literacy and Cervical Cancer Screening Among Mexican-American Women

Bertha E. Flores, PhD, RN, WHNP-BC; Gayle Acton, PhD, RN, CS; Lyda Arevalo-Flechas, PhD, RN; Sara Gill, PhD, RN; and Michael Mackert, PhD

ABSTRACT

Background: Health literacy is a requisite skill for making personal health and health care decisions. Low health literacy may contribute to lower cervical cancer screening rates and cervical cancer health disparities among Mexican-American women in South Texas. Objective: To explore older Mexican-American women's health literacy related to cervical cancer from the perspective of Zarcadoolas, Pleaseant, and Greer's health literacy model. Methods: We conducted five focus groups and seven individual interviews with 30 Mexican and Mexican-American women in South Texas. We analyzed demographic data using descriptive statistics and conducted thematic analysis of focus group and individual interview data. Key Results: Several themes reflected the domains of health literacy, including fundamental literacy ("speaking of language"), science literacy (cancer prevention), cultural literacy ("we are different"), civic literacy (the availability of "consejos" [advice]), and media literacy (e.g., "telenovelas" [soap-operas] teach a lot). In this article, we present findings related to culture and language under the domains of fundamental and cultural literacy. Conclusions: Mexican-American women's cultural values and language use may serve as both deterrents and incentives to cervical cancer screening. The meaning of words can be lost in translations. Health care providers can use this information to provide cervical cancer screening education congruent with Mexican-American's culture, language, and code switching. [HLRP: Health Literacy Research and Practice. 2019;3(1):e1-e8.]

Plain Language Summary: The understanding of culture and language can help health care providers improve cervical cancer screening practices among Mexican-American women. The results from this study can be used to individualize patient care and to develop education and communication strategies that are similar to the population we serve, including Mexican-American women.

Health literacy is defined as "the wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life" (Zarcadoolas, Pleasant, & Greer, 2005, pp. 196-197). Health literacy skills are critical because they affect health and health behaviors (Kindig, Panzer, Nielsen-Bohlman, 2004). Persons with low health literacy are more likely to have decreased use of health care services (Berkman et al., 2011) and lower rates of cancer screening (Oldach & Katz, 2014). In addition, women with low health literacy scores are less likely to have had a Pap smear compared with those with high health literacy score (34% vs. 59%, p < .0001) (Heberer et al., 2016). Based on these premises, it is appar-

ent that low health literacy is an extremely important public health problem in the United States.

A literature review conducted to evaluate the links between health literacy and cervical cancer screening reported a positive relationship between health literacy and Pap smear test (Kim & Han, 2016). Although many studies include multiethnic groups of women (Kim & Han, 2016), few have reported on Hispanic women. A study conducted with Hispanic women noted the relationship between low Pap smear screening and low health literacy and reported that Spanish-speaking women (n = 205) with inadequate health literacy were 16.7 times less likely to have had a Pap smear when compared to women with adequate health literacy (Garbers & Chiasson, 2004). Indeed, the consequences of

low health literacy reach far beyond lower use of preventive screening. However, Hispanic women continue to be a high-risk group for cervical cancer (Scarinci et al., 2010); in particular, Texas is a region with disparities in Hispanic cervical cancer mortality (Lin & Zhan, 2014).

It is recommended that women start cervical cancer screening at age 21 years (American Cancer Society, 2017); however, Hispanic women in the U.S. remain under-screened compared to non-Hispanic Whites (77% vs. 83%, respectively) (Siegel et al., 2015). The lower extent of screening may lead to higher incidence of invasive cervical cancer in Hispanic women compared to non-Hispanic Whites (Barnholtz-Sloan et al., 2009). Among Hispanic subgroups, Mexicans have the lowest cancer screening rates (Cokkinides, Bandi, Siegel, & Jemal, 2012). Low health literacy may contribute to low cervical cancer screening rates among Mexican women living in the U.S.

RESEARCH AIM AND CONCEPTUAL FRAMEWORK

The aim of this research was to explore health literacy as it relates to cervical cancer screening among older Mexican-American women. The Health Literacy Model (HLM) by Zarcadoolas, Pleasant, and Greer (2006) guided the research. The HLM describes the interactions of culture, education, ethnicity, and socioeconomic differences among people. The multidimensional model includes four domains: (1) fundamental literacy or the ability to read, speak, write, and understand numbers, (2) science literacy or understanding of the scientific process, (3) civic literacy

or the awareness of public issues and that includes media literacy, and (4) cultural literacy or the ability to use beliefs and customs to interpret and act on health communication. Cultural literacy "should be bilateral," (p. 57) where the communicator understands the culture of the recipient and vice versa (Zarcadoolas et al., 2006).

METHODS

Setting and Sample

The study setting was South Texas, where the population is mainly Hispanic (Ramirez, Thompson, & Vela, 2013). After Institutional Review Board from The University of Texas at Austin approval, the primary investigator (PI) recruited a purposive sample to participate in either focus group or individual interviews. Inclusion criteria for participants included the following: (1) Mexican-American, (2) communicate in English or Spanish, (3) age 50 years or older, (4) living in a community dwelling, and (5) negative history of cancer. We posted recruitment flyers in English and Spanish at several local community senior centers, and also recruited participants through referrals. The senior centers provided a private room to conduct interviews. At the time of our study, few studies had been conducted with older Mexican-American women with reported lower rates of Pap smear screening (Flores, 2012; Flores & Acton, 2013).

Procedures

Data collection was conducted from January 2012 to May 2012. It included five focus groups and seven individu-

Bertha E. Flores, PhD, RN, WHNP-BC, is an Assistant Professor, University of Texas Health Science Center at San Antonio, School of Nursing. Gayle Acton, PhD, RN, CS, is an Associate Professor, University of Texas, Austin School of Nursing. Lyda Arevalo-Flechas, PhD, RN, is an Advanced Geriatrics Fellow, and a John A. Hartford Claire M. Fagin Fellow, Geriatric Research, Educational & Clinical Center, South Texas Veterans Health Care System. Sara Gill, PhD, RN, is a Professor, University of Texas Health Science Center at San Antonio, School of Nursing. Michael Mackert, PhD, is an Associate Professor, Stan Richards School of Advertising & Public Relations, The University of Texas at Austin.

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Address correspondence to Bertha E. Flores, PhD, RN, WHNP-BC, John A. Hartford BAGNC Scholar (09-11), UT Health San Antonio, School of Nursing, 7703 Floyd Curl Drive, San Antonio, TX 78229-3900; email: floresb2@uthscsa.edu.

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al interviews aimed at exploring health literacy as it relates to cervical cancer screening among English and/or Spanishspeaking older women of Mexican ancestry. We developed a moderator guide based on the four components of the health literacy model: fundamental literacy, science literacy, cultural literacy, and civic literacy (Zarcadoolas et al., 2006). A bilingual/bicultural panel of four professional nurses working in South Texas and familiar with the Mexican culture and language agreed on questions and translations. The panel included the following: the first author, B.E.F., who was born and raised in Mexico, educated in Texas, is a bilingual/bicultural women's health care nurse practitioner, the PI, and the focus group moderator; a co-author, L.A.F., who is a Colombian-born nurse and co-moderator; another bilingual women's health care nurse practitioner; and a Mexican-American nurse who was born and raised in Texas. The panel members were familiar with speech patterns of Hispanics, primarily of Mexican descent who are bilingual and living in Texas.

Focus groups were comprised of three to eight participants. Given the sensitivity of the subject matter, we also conducted seven individual interviews, which are often combined with focus groups (Morgan, 1998); data saturation was reached with 30 participants. The PI conducted all focus group and individual interviews. Demographic data collected were referenced with a pseudonym and included (1) age, (2) marital status, (3) education level, (4) preferred language, and (5) ethnicity by self-report. The reports are for group (N = 30) demographics and provide further anonymity (Table 1). Interviews were audio recorded and transcribed word-for-word in the original language. Upon completion of interviews, each participant received a \$30 gift card, a list of low or no cost Pap smear services available, and general information about cervical cancer screening. The majority of participants (79%) were U.S. born and 47% were English speakers. Interestingly, 23% of all participants equally chose English and Spanish as the primary language. Demographic analysis for the group (N = 30) is reported in **Table 1**.

Data Collection

Focus group interviews were segmented by participants' preferred spoken language (i.e., English or Spanish). Each participant chose a pseudonym from a prior generated list. Participants were seated around a table in a private room. As is customary in Hispanic culture, refreshments, pleasantries, and conversation took place before and after interviews. As part of the moderator guide, questions were used to elicit knowledge, beliefs, and customs related to cervical cancer screening (Table 2). A summary was presented at the end of each interview to validate constructs and to add or withdraw

information. The PI conducted all interviews, and interpreters were not used. In addition, the co-moderator took field notes of group dynamics and nonverbal communication.

Data Analysis

Translation procedures followed the process outlined by Chen and Boore (2010). They posit that after verbatim transcription of the content in original language and subsequent analysis of content, two bilingual translators are necessary to translate the emerged concepts and categories. Two bilingual/bicultural translators (PI and co-moderator) agreed on all translations. The translation was for meaning (Espocito, 2001) and conducted by the PI who is familiar with the culture and language (Medrano et al., 2010). The first step was to select unit categories after major headings from the HLM as described by Zarcadoolas et al. (2006). Then the data were organized after an individual matrix, and developed and analyzed in a case-by-case variable matrix (Bernard & Ryan, 2010), then grouped in categories and themes under the major health literacy domains. After abstracting themes and subthemes used to report results, we developed matrices for each interview. Each matrix was initially analyzed separately and later analyzed together (Miles & Huberman, 1994). Dissertation committee members and coauthors met regularly with the PI to discuss translations, codes, themes, and subthemes. Trustworthiness and credibility were established (Lincon & Guba, 1985) through communication among committee members, use of field notes, peer debriefing, and member check. Descriptive statistics were used to analyze descriptive data using Excel and SPSS 19.

RESULTS

In this article, we discuss 2 of 4 major themes that correlate to the domains of the HLM related to culture and language (Zarcaroolas et al., 2015): fundamental literacy (speaking of language) and cultural literacy (we are different).

Fundamental Literacy

Fundamental literacy or the ability to read, write, speak, and interpret numbers is needed to understand health information (Zarcadoolas et al., 2005). One of the themes under this domain is speaking of language. Although we recruited participants for either English or Spanish interviews, code switching was common in all interviews conducted. Code switching is used as a means of switching from one language to another (English-Spanish code switching or "Spanglish" [Martinez, 2010]) was used by participants, which is common speech among bilinguals in Texas. Therefore, we find it important to include Spanish words, codes, and themes in

TABLE 1

Summary of Group Demographics $(N = 30)^a$

Characteristic	Percentage
Place of birth	
United States	79
Mexico	21
Marital status	
Married	47
Divorced	27
Widowed	26
Ethnicity	
Mexican-American	77
Mexican	20
No answer	3
Primary language	
English	47
Spanish	30
English/Spanish	23
Education	
<high school<="" td=""><td>27</td></high>	27
High school	20
>High school	53
Health insurance	
Medicare	73
Private	17
None	3
Not reported	7

^aAverage age: 71 years.

our findings. Spanish-speaking participants did not know the word Papanicolaou, which is commonly used in Spanish for Pap smear. Participant's comments included, "Papanicolaou, maybe it is food" and "It sounds funny en Español [Spanish]." Others said: "Does not mean anything," "The name does not focus me on the reason," "La palabra no te imaginas lo que es. No te reportan en la realidad" [you don't imagine what the word is. It does not help you focus on the reality], and "aunque hablen en Español, le dicen Pap smear" [even if they speak Spanish, they say Pap smear]. Furthermore, many participants received formal education in the U.S. and could not read in Spanish. Among English-speaking participants, the word "embarrassed" was often code switched to the Spanish word vergüenza [embarrassed]. In addition to code switching, there was lack of understanding

TABLE 2

Sample Moderator Questions: Cultural Literacy and Pap Smears

- What is the general attitude among your friends and family regarding Pap smears?
- Is there anything in your culture that affects your views? Tell me about that.
- Are there any religious or cultural pressures that make it hard to obtain a Pap smear?
- Did your mother talk to you about Pap smears?
- Would you talk to your younger family members (daughters or granddaughters) about Pap smears?
- What would your advice be to women about Pap smears?

From "Las Doñas" health literacy and cervical cancer screening among older Mexican-American women, by B. E. Flores, 2012, Doctoral dissertation, The University of Texas at Austin. Author retains copyright; permission is not required.

and meaning of commonly used words in cancer education such as Pap smear.

Cultural Literacy

"Somos diferentes" [We are different] is the major theme under the domain of cultural literacy or the ability to (1) "recognize collective beliefs, world-view, and social identity in order to act on health information and the communicator's skill" and (2) "accommodate health information to cultural understandings of health information" (Zarcadoolas et al., 2005, p. 197). This domain was interwoven across all other domains of health literacy; therefore, it is the central domain presented in this report. All participants reported that Mexican-American cultural values were different than those of the main Anglo-American culture of the U.S. This theme was associated with being raised with different ideas, values, and a sense of modesty, which is best illustrated by a participant's story: "usted pudiera ver la niña Latina, pues se baña con el traje de baño, es diferente nuestra cultura" [you would see the Latina girl, well, she is the one showering with her bathing suit, our culture is different]. Hispanic girls' sense of modesty is instilled from an early age. This sense of modesty may be a deterrent to cervical cancer screening. Taboo subjects, such as sexuality and cervical cancer screening, are not discussed among family members because of vergüenza [embarrassment]. All participants said that they were raised differently than the predominant Anglo-American culture. Subthemes elucidated were (1) we did not talk about it, (2) woman provider preferred, (3) Respeto [respect], (4) some men don't like it, and (5) family first.

We did not talk about it. This subtheme was associated with lack of communication and information from mothers to daughters. Participants reported that they did not receive any information from their mothers. However, there was general agreement that open communication was needed across generations to improve health. Participants reported that certain topics are not discussed including menstruation, sexuality, and Pap smears. Some comments were "our mothers had no voice," "they never told me anything," "with my mom and my dad we could not say nothing, we were embarrassed," and "people don't talk about it."

Women reported that they learned about Pap smears during their childbearing years. The lack of motherdaughter communication was attributed in part to embarrassment. All women reported that lack of cervical cancer screening was related to embarrassment especially among Hispanic women in reference to pelvic examinations. Several participants described this sentiment: "Típica Latina, somos más vergonzosas" [typical of Latin women, we are very embarrassed] and "vergüenza, ojos cerrados, tiesa" [embarrassment, closed eyes, rigid]. While another participant, referring to her mother said, "she hated it because it was something really embarrassed to her," and another participant said, "a lot of women are embarrassed to go to the procedure especially Hispanic women." A vivid discussion ensued among the women in which they agreed that open mother-daughter dialogue and overcoming embarrassment were imperative to safeguard the health of future generations. Participants suggested the following advice be given to enable other women to overcome their embarrassment: see a woman provider, make examinations routine, obtain accurate information, and realize the importance of the test.

Woman provider preferred. One way to overcome embarrassment is to seek an experienced woman provider. They said that women providers increased comfort, decreased embarrassment, and made it easier to attend cervical cancer screening. Participants' comments included "women are more comfortable with women" and "a woman is more familiar with what we go through." Many preferred a woman nurse practitioner and described the experience as comfortable and relaxed. Participants' comments were "I feel free to talk to a nurse," "nurse practitioners are more thorough," and "I would rather have a nurse, female."

All participants expected Hispanic core values such as personalismo (personal, friendly), simpatía (friendly, polite), and confianza (mutual trust among individuals) (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008; Castillo, Perez, Castillo, & Ghosheh, 2010; Padilla & Villalobos, 2007) to be important during the health care encounter and is an incen-

tive to attend cervical cancer screening. Participants noted the importance of having "a good relationship" with the health care provider and highlighted positive relationships with women physicians (e.g., "my doctor is a lady, and I get along really great, we discuss everything"). Of note, having a personal connection with a provider regardless of gender was valued (e.g., "I have a good relationship with my gynecologist, he is like family" and "know the person for a long time"). Incentives to continued cervical cancer screening included having a trusted provider with good listening skills who embodied Hispanic cultural values.

Respeto (respect). Another subtheme was the Hispanic core value of respect. All participants said that teaching sexual health education must be provided with respect to Hispanic girls. Health care educators must be keenly aware of the importance of teaching and giving consejos (advice) to Mexican-American girls with respect. Information about women's health care issues, such as Pap smears and sexuality has to be given with truth, firmness, and respect. One participant said, "schools should have classes for women alone," and another one noted, "the teacher or nurse should be very, very serious and firm." The Mexican-American value of respect was unanimously seen throughout all interviews. In addition, self-respect included the value of marianismo [traditional role of women in Hispanic culture], which was noted in the interviews. It is an expectation that women will accomplish their role as a woman. A participant said, "women were expected to wait until marriage before initiating sexual activity where the men are muy macho [male Hispanic characteristic] (Arciniega et al., 2008; Castillo et al., 2010; Padilla & Villalobos, 2007) with multiple sexual partners "y la mujer no, nada, que la fregada!" [and the woman, no, nothing, what a mess]. Gender roles, family values, and perceived lack of partner support from their men were important deterrents to cervical cancer screening among these older Mexican-American women.

Some men don't like it. Another subtheme associated with a deterrent to cervical cancer screening among Mexican-American women was perceived lack of partner support or machismo (traditional characteristic role of Hispanic men) toward cervical cancer screening. Participants reported that some Mexican men do not let their wives go to their gynecological examination and said, "por machistas, y más el Mexicano" [because they are very manly, especially the Mexican male] and "they just don't like it; some men are like that," and "husbands won't allow it or their culture or how they were brought out." Women understood that their health was most important and in the case of cervical cancer screening, lack of support from a man had to be disregard-

ed, i.e., "Que te valga Chencha" [don't give it importance] (phrase used in Mexico).

Family first. Another subtheme associated with a deterrent to cervical cancer screening was familismo [the family]. The family refers to women's ideals and dedication to take care of the family first (Arciniega et al., 2008; Castillo et al., 2010; Padilla & Villalobos, 2007). Putting family's priorities ahead of one's needs leaves little time for self-care, including appointments for preventive health care such as Pap smears. Typical reasons included: "El valor, la unidad familiar que existe en nuestra cultura es muy diferente" [the value, the family unity that exists in our culture is very different], and "Mexican women are very close to their families and their families are very important and they let themselves go, they do not think about themselves, they think about their sons and their daughters, the family first." Another participant said: "es la familia ¿ verdad? Y nos olvidamos de nosotros" [It's the family, right? And we forget about ourselves].

DISCUSSION

The Mexican and Mexican-American women who participated in this research reported some degree of familiarity with Pap smears. However, terms used in cervical cancer education did not have meaning for them. For example, Spanish-speaking participants had not heard of the Spanish word, Papanicolaou, which is used for Pap smear. Similarly, researchers have reported that few women recognized terms in Spanish for such words as cervix and uterus (Hunter & Kelly, 2012). In contrast, a recent cross-sectional survey found that Spanish-speaking women were less likely to choose the wrong description for Pap smear compared to English-speaking women (Howard, Soulli, Johnson, & Cooper, 2016). It was noted that Spanish-speaking participants did not read or write in Spanish; instead they were able to read and write in English. This may be because one-third of Mexicans living in the U.S. are bilingual and 73% speak Spanish at home (Lopez, 2015). These findings suggest that translations alone may be inadequate in cervical cancer prevention education. A thorough understanding of biculturalism and bilingualism in South Texas is essential to deliver health messages that are understood by the community.

Deterrents and/or incentives to cervical cancer screening among older Mexican-American women were associated with cultural values and beliefs, respect, personal, friendly, machismo, marianismo, family first, preference for women providers and embarrassment. Similar to findings reported by Fernandez et al. (2009), the women that participated in these interviews used words such as machismo to describe male gender roles. These are common cul-

tural values that have been previously described as central to Hispanic culture (Arciniega et al., 2008; Castillo et al., 2010; Padilla & Villalobos, 2007). Attending to the assertion that "we are different," health educators and providers should frame and develop individual and collective messages to empower Mexican-American women to continue recommended cervical cancer screening. Although some participants were beyond the recommended age for screening, influential family members such as grandmothers can influence younger women's preventive practices.

Embarrassment was a clearly identified factor contributing to lack of cervical cancer screening. Despite these challenges, our participants were eager to learn and break down communication barriers to improve the health of younger generations. Galanti (2003) described similar findings of modesty and female-male roles being barriers to cervical cancer screening among older Mexican-American women. Furthermore, sexuality is a private matter and not discussed among Hispanic family members (Parra-Medinaet al., 2009) and embarrassment has been described as a barrier to cervical cancer screening among Hispanic women (Szalacha, Kue, & Menon, 2016). Although not reported by these participants, Baezconde-Garbanati, Murphy, Moran, and Cortessis (2013) noted that younger Latina women perceived that older women associate Pap smears with promiscuity.

Preference for women providers helps overcome embarrassment. This finding is consistent with Randolph, Freeman, and Freeman (2002) who reported that a predictor for recent Pap smear among older Mexican-American women in Texas was a woman provider. Similarly, authors have described that a barrier to cervical cancer screening among Hispanic women is the lack of Spanish-speaking women providers (Boyer, Williams, Callister, & Marshall, 2001). The importance of mutual respect, including the idea of self-respect, was unanimously reported in all interviews. Findings from this study complement previous results, where disrespect during the health care encounter was described as a barrier and modesty reported as an obstacle to cervical cancer screening among Hispanic women (Szalacha et al., 2016).

Gender role expectations of marianismo and machismo can deter cervical cancer screening (Galanti, 2003). Women are expected to postpone sexual activity until marriage whereas men's roles are the opposite. Participants reported lack of partner support for Pap smears and further added that educational campaigns need to include men. Our results are similar to those observed in one study conducted in California. Similar to our findings, Baezconde-Garbanati

et al. (2013) reported women's belief that husbands might not approve of the Pap smear procedures was a barrier to seeking care. The present study did not include men; however, in a focus group study conducted with Mexican men and women, researchers concluded that after providing information about human papillomavirus infection, men wanted to take responsibility, get tested, and displayed positive machismo (Fernandez et al., 2009).

Family first was noted to be a deterrent to cervical cancer screening in this study. Women reported that caring for family members and putting family first left little time available for self-care. Similarly, self-care has been reported to have less importance than caring for the family (Galanti, 2003). This is similar to recent research as authors report that the family is both a barrier and a facilitator. Family can have a positive impact on cervical cancer screening, as well as be a barrier when the "family first" way of life takes priority over self-care (Madhivanan, Valderrama, Krupp, & Ibanez, 2016).

STUDY LIMITATIONS

Limitations of the study include a purposive sample and data collected from one area in South Texas, which constraints generalizations. Further research is needed to address the specific needs of Mexican-American women, generational gaps, and the inclusion of men. With the major theme, "We are Different," this study attests to the importance of the inclusion of cultural literacy to deliver care to diverse people, including Mexican-American women.

IMPLICATIONS

Cultural information without stereotyping can be a valuable tool to provide health care congruent with community values. Similar to Galanti (2003), the information presented here is for generalizations. According to Galanti (2013), the difference is on how the information is used: "a stereotype is an ending point; a generalization is a beginning point" (p. 180). In this study, we used direct quotations from the women; this theme can help to develop individual and collective messages to empower Mexican-American women to continue recommended cervical cancer screening. All health care providers can make lasting contributions to patients' health care by assessing health literacy and provide education, communication, and care appropriate for all people and communities.

CONCLUSIONS

Practitioners need to recommend cervical cancer screening, provide information congruent with the person's

health literacy, education, culture, and socioeconomic status, as well as provide environments conducive to mutual respect. Lack of cervical cancer screening among Mexican-American women is multifactorial. Providers can make a concerted effort to provide care congruent with Hispanic cultural core values because they can be deterrents and incentives to cervical cancer screening. In this research with Mexican and Mexican-American women in Texas, many participants reported that cultural deterrents to cervical cancer screening had to be overcome to improve their health and the health of future generations. They noted that they would initiate a conversation with their family members about the importance of testing; they were indeed eager to receive information to pass along to younger generations and urged us to continue our work. This research adds to the importance of a bidirectional definition of cultural literacy. Women recognized and understood the influence of culture on their health care practices and felt strongly that those barriers needed to be eliminated or overcome. Our study has implications for health care education; one that includes expected cultural values, language, and norms. In all, it is imperative to assess cultural values in practice, communication, education, and health policy as an important step toward eliminating cervical cancer health disparities.

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