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ORIGINAL ARTICLE

Leaving footprints, not scars: a qualitative pilot study of Hispanic mothers' willingness to communicate with dependent children about an advanced cancer diagnosis

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Abstract

Purpose US Hispanics are more likely to be diagnosed with advanced cancer as parents than their non-Hispanic white counterparts but little is known about Hispanic parents' willingness to discuss a terminal cancer diagnosis with dependent children, potentially resulting in suboptimal child coping. Therefore, we investigated Hispanic mothers' willingness to communicate with dependent children about her actual or hypothetical advanced cancer diagnosis.

Methods Two focus groups ($n = 6$ participants) and three one-on-one interviews ($n = 3$) were conducted in either Spanish or English among adult, Mexican-American mothers with a current cancer diagnosis of any stage residing in US-Mexico border communities. Participants reported their perceived concerns, parenting challenges, and openness to discussing an incurable cancer diagnosis with a dependent child. Audio files were transcribed into English and qualitatively coded using content analysis.

Results Participants, most with breast cancer, ranged in age from 25 to 47. Five had considered the possibility of their own death from advanced cancer and three had previously discussed this with their children. While many expected their children would carry on well without them, seven expressed concern for the emotional/spiritual well-being of their children. Mothers anticipated physical and time-based parenting challenges but wanted the opportunity to focus on themselves and their children in advance of death. All but one would be willing to discuss an advance cancer diagnosis with dependent children; four expressed the value of doing so or the potential harm of abdicating this responsibility.

Conclusions If faced with an advanced cancer diagnosis, Mexican-American mothers are open to communicating with dependent children.

Keywords Palliative care · Cancer · Hispanic Americans · Child · Adolescent · Terminally ill · Parenting · Communication · Child of impaired parents · Parent child relations

Introduction

The Hispanic population comprises approximately 55 million American individuals (17.6% of the US population) and is expected to grow to 119 million in 2060 (28.6% of the US population) [1]. Hispanics are one of the fastest growing minority groups in America (2.3% annually) [2], second only to Asians. Among Hispanics, cancer is the leading cause of death (22% of all mortality), despite relatively low incidence rates compared to non-Hispanic White (NHW) populations [3]. Unfortunately, Hispanics are more likely to present with aggressive or hard to treat cancer subtypes including liver, biliary, gallbladder, stomach, and cervical cancer, as well as more advanced cancer [3]. Hispanics are also more likely to be diagnosed with cancer at a younger age. Twenty five percent of cancer diagnoses in Hispanics occur in individuals 50 years of age or younger, compared to 12% in NHWs [3].

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These facts suggest Hispanics may be at greater risk of developing cancer during their childbearing years. This, and the fact that 60% of the growth in the US Hispanic population is due to births [2], implies that Hispanic cancer patients may be more likely to have children in the home at the time of their cancer diagnosis than their NHW counterparts. Estimates suggest approximately ½ million American children are living with a parent in the early stages of cancer treatment and 55,000 may experience parental death from cancer each year [4]. Both children and parents suffer in this context. Literature suggests parents with a cancer diagnosis are more distressed [5] and their children may also experience negative changes in emotional, social, behavioral, cognitive, and physical functioning that are attributable to the parent's cancer [6–9]. In particular, internalizing problems such as anxiety and depression may be greater in children whose parents have cancer.

While a significant amount is known about the experience of NHW parents' communication of a cancer diagnosis with their dependent children, very little is known about the specific experience of Hispanic parents. We were particularly interested in the experience of Hispanics given the known difficulty of parental cancer communication and existing studies which suggest Hispanics may be less willing to discuss end of life issues (such as advance care planning or hospice referral) [10–13]. If Hispanic parents are also less willing to disclose and discuss a cancer diagnosis with their dependent children, then the experience of parental cancer may be unique for Hispanic children. Furthermore, Hispanic parents with cancer may require culturally competent, specialized interventions to promote positive communication.

While one manuscript has discussed disclosure to family members by women of various racial and ethnic backgrounds, including Hispanic women [14], we were unable to find an English-language, peer-reviewed journal article devoted exclusively to disclosure and communication between Hispanic parents with cancer and their dependent children that was published within the last 10 years. Therefore, this qualitative pilot study used focus groups and one-on-one interviews with Mexican-American women diagnosed with cancer who also had a dependent child (ren) living in the home to explore their thoughts about communicating an advanced cancer diagnosis to their children.

Methods

The Institutional Review Board at New Mexico State University approved the research protocol for this qualitative study on October 10, 2016 (#13963). Prior to qualitative data collection, participants provided written informed consent to participate in a focus group or individual interview and to be audio recorded. All qualitative data were collected between November 30, 2016, to March 8, 2017 as one-time focus groups (two groups, 3 participants each, $n = 6$) and 3 individual interviews ($n = 3$) to accommodate women who could not or declined to attend a focus group. All interviews were conducted as part of a larger project designed to culturally adapt a communication intervention for Hispanic parents with cancer [15].

Subject recruitment and participation

Participants represented a convenience sample recruited via a variety of sources, including various media outlets (radio, TV, newspaper, Facebook), flyers distributed through federally qualified health centers and community agencies (e.g., Health and Human Services, social workers, libraries), and cancer support groups on the border region in New Mexico and Texas, USA. Participants called project staff to be screened and consent for the study. All participants received information regarding the study in their preferred language (English or Spanish). Eligibility criteria included being a Hispanic mother, having a cancer diagnosis of any stage within the last 2 years, having a child 5 to 12 years old living in the household, and living in either of two targeted border counties (Dona Ana, NM, or El Paso, TX).

Staff scheduled the individual interviews and focus groups at locations most convenient to participants (e.g., community center, work office, or home). Focus groups and individual interviews were conducted in the language preferred by the research participants. All were conducted in a private room without children or other family present. The purpose of the study was provided and a little information about the researchers at the start of the interview/group. At focus groups, the moderator and two notetakers were present, while individual researchers conducted the interviews. The moderator for all focus groups and individual interviews was fluent in both English and Spanish. At least one research assistant (note taker) in each focus group was fluent in both English and Spanish. Prior to beginning, participants in focus groups agreed that shared information was confidential and would not be discussed outside of the room. All participants received a meal and $25 gift card upon completion of the interview or focus group.

The same structured interview guide was used for both focus groups and individual interviews. Participants were asked whether they were willing to participate in a part of the study, which required them to imagine what it would be like to be a mother diagnosed with an advanced cancer that could not be cured. All participants agreed to participate in this segment of the study. Questions included in the present analysis were: 1. "If you had advanced cancer and could not be cured, what do you think would be your major concerns regarding your children?", 2. "What would be your greatest parenting challenge if your cancer was advanced?", and 3. "If you had advanced cancer, would you be willing to discuss your cancer with your child?" Questions were assessed prior to use using cognitive interviewing with bilingual Hispanic public health students with native-speaker fluency in both

English and Spanish. Probes were used to clarify or encourage elaboration as appropriate.

Qualitative analysis

Focus groups and individual interviews were audio recorded, transcribed into English, and checked for accuracy by bilingual research staff. Research subjects did not review the transcripts or the analysis results. The methodologic approach was based in critical realism (ontology); qualitative coding was conducted using content analysis, using an inductive, semantic approach from the realist perspective [16]. This method was selected in light of the small number of transcripts and relative lack of prior publications and theory on this topic. The analysis process closely followed the six phases outlined by Braun and Clark [16], beginning with both reviewers independently reading the transcripts at least 3 times while taking personal notes. All text within a transcript was then coded by hand, focusing on the words used by the speaker.

Reviewers then compared their initial findings to identify and reconcile any differences. Coding and recoding followed an iterative process. The most frequently occurring codes identified in the data were compared across transcripts using the individual as the level of analysis. Themes were named, defined, and compared by the two analysts and differences were again resolved via consensus. The analysts then selected representative quotations for the identified themes. While we do not believe data saturation was achieved, the results represent all major and minor themes occurring across more than one transcript. Primary data is under the authors' full control and may be obtained by contacting the corresponding author.

Results

Participants were accessed through community recruitment and referral, including Facebook ($n = 2$), friend referral ($n = 2$), cancer organizations or support groups ($n = 3$), and other community sites (e.g., medical centers, schools) where flyers were distributed ($n = 2$). The nine study participants ranged in age from 25 to 42 years old. Two participants reported Spanish as their preferred language. One of these participated in an individual interview conducted exclusively in Spanish. The other participated in a focus group conducted in both English and Spanish. Most were married (67%), had multiple children (78%), had more than high school education (78%), and were employed (67%) at the time of study participation. Slightly more than half reported a breast cancer diagnosis (56%). Five participants had advanced disease (Stages III or IV). See Table 1 for additional demographic information about the sample.

Table 1 Participant demographics

Characteristic	Total (percentage) $n = 9$
County of residence	
Doña Ana, NM	5 (56%)
El Paso, TX	4 (44%)
Age (years)	
< 30	1 (11%)
30–39	4 (44%)
40–49	4 (44%)
Marital status	
Married	6 (67%)
Single	2 (22%)
Divorced	1 (11%)
Current employment	
Yes	6 (67%)
No	3 (33%)
Education	
High school or less	2 (22%)
Some college, no degree	2 (22%)
Associate's degree	3 (33%)
Bachelor's degree	2 (22%)
Preferred language	
English	4 (44%)
Both English/Spanish	3 (33%)
Spanish	2 (22%)
Cancer diagnosis	
Breast	5 (56%)
Thyroid	2 (22%)
Ovarian	2 (22%)
Stage of cancer	
Stage III	3 (33%)
Stage IV	2 (22%)
Unknown	4 (44%)
Age at diagnosis (mean = 34.67)	
< 30	2 (22%)
30–39	6 (67%)
40–49	1 (11%)
Age of children currently in the home ($n = 14$)[a]	
5–6 years	3 (21%)
7–9 years	4 (29%)
10–13 years	7 (50%)

[a] Participants could have more than one child

Prior considerations

Regardless of personal stage of disease, five study participants had considered the possibility of developing advanced cancer and/or their own death. Participant 4: "It's crossed our minds. So as much as we don't want to consider, myself, I don't want to consider myself advanced or incurable, I've been there."

Most had already discussed the possible eventuality of their own death with adult family members or friends, including, for example, specific plans regarding the care and custody of their child (ren). Three mothers had previously discussed this topic with their own children. Of note, three had experienced the death of a parent or close family member and shared how that experience either affected them or would influence their behavior if they were dying.

Parenting challenges

Mothers anticipated several distinct parenting challenges with advanced cancer. Two mothers expressed concern about their physical or mental inability to provide for the needs of their children, with one mother noting that this challenge also existed with early-stage treatment on chemotherapy. Participant 1: "So, that's, I mean, that's a parenting challenge, not to be able to take them out, or even, you know, like doing the homework because you have chemo brain or you know, just helping them." The feeling of not having enough time was mentioned by one subject, and appeared also within two other themes entitled "competing needs" and "changing expectations." Participant 5: "I guess, you know before everything was cool and laid back and now, now I feel like I need to, I need to hurry up and do all these things with my son."

Three mothers expressed the challenge of balancing their own desires and needs with the needs of their children—a challenge made more complicated by the possibility of limited time due to an incurable cancer. One mother feared that the lack of time to do everything made her appear selfish but also limited her ability to provide everything she wanted to for her son who was developmentally not ready for all of the "life lessons" she wanted to provide. Having limited time with children was also a factor within the theme of "changing expectations." One mother expressed the challenge of knowing what was important (or not important) when correcting the child's behavior. Participant 9: "I mean expectations of like, picking your battles you know? What's most important?...I think I would let a lot of things slide and I don't know if that would necessarily be a positive thing for her." This mother expressed a fear of spoiling her child because she would not want the remaining limited time marked by conflict; thus, she feared altering the expectations she would have had of her child if she were not dying of cancer.

Concerns for their children

Mothers also expressed several concerns for their children. Four mothers expressed concern about the tangible needs of their children. Specifics such as with whom the children would live, the logistics of care by a single parent, and whether money would be tight were examples. Participants also worried about how children would manage without a mother during life's formative events. However, the most common overarching concern for these mothers was for the emotional ($n = 5$) and spiritual well-being of their children ($n = 2$). Two feared the pain and anger a child might feel toward God. Participant 6: "Um, also that they will lose faith in God, you know, that they become resentful of him and feel rage against him."

Confidence the children will be okay

Despite these concerns, four mothers were confident their children would be okay despite their death. They cited the strength of the children, the attainment of meaningful milestones, and family support as protective factors for the children. Two women also suggested that children are resilient in the face of parental death, despite the inevitable pain. One woman (Participant 4) drew upon her own experience with the death of her father stating, "for as much as it sucked, the sun still comes up and the sun still sets every single day."

Hopes and expectations for their children

Four mothers also expressed their hopes and expectations for their child (ren) even after their death. They wanted to prepare and shape their children in advance of their passing. This included conveying how they wanted them to conduct themselves (e.g., to "be strong") but also to encourage them to be their best selves and to plan for, and follow, their dreams. Participant 7: "And well I say that in one way one should anticipate things and say, "Tomorrow if I am not here I would like that every one of you, um, tell them what I would want them to be or what I expect of them."

Advanced cancer as an opportunity for positive change

Advanced cancer was not viewed simply as a difficult or challenging experience. Three mothers expressed that advanced cancer was an opportunity, which could or did facilitate positive change in their lives. Two mothers described having advanced cancer as a potent reminder to live each day to the fullest and to be grateful for simple things like seeing their children's faces. Participant 2: "But, I don't think it would be a challenge. I would think it would allow me to let go of the everyday stuff that is not important so I can live every day to the fullest with them." Two mothers would use the time before death to create a legacy for their children, including creating the best possible memories. Participant 6*:* "I think that the long or short amount of time I would have left, you know, I would give it to them in kindness. I would leave, um, my best memories … And, um, instead of leaving a scar, I would leave a footprint for them."

Communication with their child (ren) about advanced cancer

All but one mother ($n = 8$) explicitly stated they would discuss an advanced, incurable cancer diagnosis with their child (ren). The one woman in our sample with advanced cancer (Participant 5) who had previously discussed the incurable nature of her disease said, "I found a way, and I let him know, you know, that this will be forever …" . Subjects acknowledged the difficulty of ($n = 4$), and barriers ($n = 3$) to this kind of conversation, including not knowing the best choice of words, an uncertain life expectancy, and the inability to reassure their child (ren) that everything would be okay when a cure was no longer possible. However, two mothers discussed the value of having the conversation and the opportunity open communication provided to help children better cope while one was still living. Furthermore, two other subjects suggested *not* preparing the child for parental death could be harmful, leaving the child feeling "cheated" or "shocked." Participant 1: "But, I would assume, I would think it's a bigger shocker for those kids to have to, you know, just watch their parents slowly die and not be told what happened. And then they feel cheated of 'Hey, you didn't tell me, you didn't give me the opportunity to be, to be part of you in a different way.' Or make every day count in their own way. You know?"

Discussion

To our knowledge, this pilot study is the first English language study focusing exclusively on child-rearing Mexican-American mothers' willingness to discuss an advanced cancer diagnosis. Our results suggest Mexican-American mothers would be willing to discuss an advanced cancer diagnosis with their dependent children. Our findings echo previous studies of parental communication and serious illness in which concerns regarding physical limitations, the significance of limited time, and the importance of preparing the child both for parental death and independent living were highlighted [9, 14, 17]. The critical importance of the child's emotional well-being (to parents) and the potentially positive influence of advanced cancer refocusing priorities toward personal growth or family relationships has also been previously noted.

It is uncertain whether our finding that at least 56% of participants had contemplated their own death represents a high or low number (particularly relative to non-Hispanic white mothers). Previous studies have reported higher rates of cancer-specific fatalism among both Hispanic men and women compared to non-Hispanic Whites and other minority groups [18–21]. This belief appears related to other health behaviors (such as cancer screening) [18], but may not be simply a function of acculturation [19]. It is also notable that at least three participants had experienced parental or close family death despite the young age of participants. Whether this reflects a higher mortality rate in this population, a fluke of recruitment or a biased sample of participants is unknown.

Our study findings should be viewed with caution. Data saturation was not reached, nor was this expected given the pilot nature of the research and small sample size. The limited number of communities, small number of subjects, and convenience sample are threats to the generalizability of our results. While some might argue that focusing only on Hispanics of Mexican descent is a limitation, this can also be viewed as a strength. Clearly, the limitation is the lack of insight into other Hispanic subtypes (i.e., Puerto Ricans, Colombians). Regardless, limiting this pilot sample to a single Hispanic population allowed us to focus our attention, particularly when evaluating whether a communication intervention might require cultural adaptation for the population of interest. In this context, lumping together various Hispanic subgroups who may have differing views regarding communication with dependent children would have been a flaw in the study design. Further, the current research serves as a jumping off point for future research including studies involving other Hispanic subtypes.

Finally, almost all participants had early stage cancer, not advanced cancer. Therefore, the answers to the study questions offer important insights but must be viewed as speculative, not based on the mothers' actual lived experiences. However, the fact that participants did have a recent cancer diagnosis is a strength relative to studies which ask about hypothetical scenarios among healthy subjects. While no implications for practice can be derived at present, clinicians working with Hispanic parents with advanced cancer should not assume Hispanic parents are unwilling to talk with their children about cancer. Similarly, while not conclusive, these results suggest that Mexican-American mothers with advanced cancer may benefit from the currently existing communication intervention following linguistic and cultural adaptations [15].

In conclusion, given the growing population of Hispanic children at risk of parental death due to cancer, and the importance of optimizing parental and child outcomes in this context, further research is warranted. Further descriptive work among a larger and more heterogenous group of Hispanic parents with advanced cancer in a qualitative study designed to reach data saturation is necessary. Results of such a study would inform a longitudinal, mixed-methods study of Hispanic parents actively facing advanced cancer, as well as their caregiver and child to address multiple outcomes of interest, including bereavement outcomes of both the child and caregiver. Results from such studies would also allow for comparison to non-Hispanic White populations and across Hispanic subgroups, as well as serve as the basis for successful cultural and linguistic adaptation in Hispanic populations of evidence-based interventions [22, 23].

Compliance with ethical standards

The Institutional Review Board at New Mexico State University approved the research protocol for this qualitative study on October 10, 2016 (#13963).

Conflict of interest The authors declare that they have no conflict to interest. Data are under the authors' full control and may be obtained by contacting the corresponding author.

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