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Qualitative Analysis of the Role of Culture in Coping Themes of Latina and European-American Mothers of Children with Cancer

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Abstract

It has been well established that mothers of children diagnosed with cancer experience high levels of distress. Latina mothers may be at risk for higher levels of distress related to language barriers, cultural factors, and economic, immigration, and acculturation stressors. Despite the increasing US Latino population, few studies have examined the role of culture within pediatric oncology, including how mothers cope with their child's cancer. This study used qualitative analysis of 24 sessions from 3 Latina and 3 European-American mothers of children recently diagnosed with cancer. The session transcripts were divided into a total of 2,328 thought segments that were then analyzed for themes using a collaborative iterative process. Analysis identified 9 shared coping themes that included, with some variations: gathering information, professional help-seeking, activities, problem solving, positive thinking, present orientation, reframing, avoidance, and religion. Three themes were culture-specific: only European-American mothers discussed compromise, while normalization and perspective taking were unique to the Latina mothers and suggest that the cultural value of *simpatía* influences coping. Clinical and research recommendations are discussed.

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Introduction

Having a child diagnosed with cancer is associated with increased distress for mothers (Kazak, Boeving, Alderfer, Hwang & Reilly, 2005; Manne et al., 2001; Sahler et al., 2005; Dolgin et al., 2007). Some research suggests this distress may be more pronounced for Latina mothers, who are often also coping with stressors associated with immigration, language barriers, acculturation, and financial hardship (Cervantes, Salgado, & Padillo, 1989; Schaefer & Pozzaglia, 1994). In addition, cultural factors may affect how Latina mothers understand their child's illness (Seigo, Gomez, & Friedenberg, 1995) and the degree of perceived trauma associated with their child's illness (Saltoun-Moran, 1988). For example, Munet-Vilaró (2004) suggested that a Latino cultural belief of fatalism (Marín & Marín, 1991) can contribute to Latino parents feeling that their child's cancer may be predetermined and beyond their control.

Other Latino cultural constructs that have been identified as impacting provision of general medical and mental health care include: dignity and respect, *familismo* (family orientation and interdependence), *personalismo* (relating on a personal level), *machismo* (positive and negative traits of traditional masculinity), *marianismo* (positive and negative traits of traditional femininity and motherhood), and religion/spirituality (Andrés-Hymen, Ortiz, Añez, Paris, & Davidson, 2006). Sharma and Kerl (2002) also discuss the importance of attending to the degree of deference accorded to authority figures and differences in time orientation when working with Latino families. Culture can also influence perceptions of health care providers and thus overall effectiveness of medical treatment. In one study, Latinos discussed their concerns with medical interactions related to language barriers, immigration and acculturative stress, negative ethnic and socioeconomic stereotypes, exclusion of family members, and feeling a lack of control (Nápoles-Springer, Santoyo, Houston, Pérez-Stable, & Stewart, 2005).

Despite the growing Latino population in the United States and continued calls to consider culture in medical settings, few studies address the role of culture in pediatric medical care (Committee on Pediatric Workforce, 2004) or pediatric psychology (Clay, Mordhorst, & Lehn, 2002; McQuaid, 2008). Within pediatric oncology, a recent review of how culture influences family management of childhood cancer found that only one out of the 19 studies reported on Latino families (Gustafson Thibodeaux & Deatrck, 2007).

The study presented here sought to expand the field's knowledge of specific coping strategies used by Latina and European-American mothers of children recently diagnosed with cancer given that coping has been identified as a key component of parental response to having a child with cancer (Lindahl Norberg, Lindblad, & Boman, 2005). Coping skills in pediatric oncology have been widely investigated (Grootenhuis & Last, 1997) and several interventions for children with cancer and their families incorporate training in coping skills (e.g., Kazak, et al., 2004; Sahler, et al., 2005); however, the influence of culture on coping style has not been previously investigated. A qualitative design within a phenomenological framework (e.g., Woodgate, 2000) was selected to gain a more detailed and nuanced understanding of the coping strategies discussed by mothers during the first months of their children's cancer diagnosis and treatment through thematic survey (e.g., Sandelowski & Barroso, 2003). Themes were compared between Latina and European-American mothers to identify possible cultural factors in their coping styles.

Method

Participants

Participants were three Latina and three European-American mothers of children recently diagnosed with cancer who participated in a larger Maternal Problem-Solving Skills Training study (see Sahler, et al., 2005) at Childrens Hospital Los Angeles. The Latina mothers were 28, 44, and 46 years old and the European-American mothers were 34, 41, and 46 years old. One of the European-American mothers also identified as having some Asian heritage. The Latina mothers had 0, 10, and 16 years of formal education and the European-American mothers had 7, 12, and 16 years of education. The mothers were all married, except for one European-American mother who was divorced. Mothers in both groups had between one and three children. The children with cancer of the Latina mothers were 2, 6, and 14 years old; two were male and one was female. The children of the European-American mothers were 4, 10, and 13 years old; one was male and two were female. The Latina mothers' children were diagnosed with ALL and AML and the European-American mothers' children were diagnosed with testicular cancer, Hodgkin's lymphoma, and neuroblastoma.

Procedure

The present study of 24 session transcriptions uses the text of four sessions with each of three Latina and three European-American mothers who participated in the problem-solving intervention in the larger study. In the larger study, participants met with mental health providers for a series of six to eight sessions over a period of four to five months. Each session lasted from 20 to 89 minutes ($M = 42$, $SD = 14$). Participants were selected randomly from those who had completed at least six sessions. The audio recordings of the participants' first, third, fifth, and final session were transcribed in order to gather data from across the course of the intervention, resulting in a total recorded time of 17 hours. Transcripts were translated into English from Spanish for the Latina mothers.

Analysis was completed using the first four analysis steps outlined by Colaizzi (1978). First, transcripts were reviewed by the first two authors to gain familiarity with the content. The transcripts were then divided into a total of 2,328 thought segments, which varied between single words to a series of sentences that reflected the smallest unit of meaning. The analysis was completed collaboratively by identifying meaning in the thought segments and grouping shared meaning into themes in an iterative process (Flick, 1998; Polkinghorne, 1991). In this study, the coping themes identified were compared for similarities and variations between the Latina and European-American mothers.

Results

Consistent with the definition of coping proposed by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141), coping skills were broadly conceptualized as any behavior or cognitive strategy that the mothers discussed as helping them deal with their child's cancer. The coping methods reported by the mothers in this study were categorized into 12 themes. These 12 themes fell into two groups: coping behaviors and cognitive coping strategies.

Coping Behaviors

Gathering information—A common coping behavior discussed by both Latina and European-American mothers was gathering information to help understand their child's diagnosis and medical treatment. They sought information from the medical team and the hospital Patient Education and Resource Center. The European-American mothers also found

information on cancer webpages, which the Latina mothers did not discuss. Unlike the European-American mothers, the Latina mothers said they relied on information from the families of other children with cancer they met in the hospital. The Latina mothers also discussed difficulty finding materials in Spanish:

“I got the information in Spanish about blood cells, it was mostly in English, but a few things in Spanish.”

Regardless of the source of information, both groups of mothers related how they felt relieved and more in control after receiving detailed information they could understand. One Latina mother said:

“My son had some kind of white blood cell count show that he can still be cancerous and the nurse explained the percentage needed to say he is clean. She explained about the red blood cells, the potassium, everything. Now I feel better.”

Professional help-seeking—Another coping behavior reported by both groups was seeking assistance from mental health and education professionals for the patient and their other children using hospital and school-based resources. One of the European-American mothers said about the patient:

“I told them we need a psychological evaluation. I mean, obviously, it’s more than we can deal with and she can deal with and we started a behavior plan.”

Mothers also sought assistance for the patient’s siblings, particularly related to school issues and their difficulty adjusting to the patient’s diagnosis and the disruption of daily family routines. The Latina mothers also discussed their own experiences with mental health professionals. One Latina mother discussed her participation in the Maternal-Problem-Solving Study:

“It’s helped me to bring my problems here in therapy and look for solutions and think what is going to help and what won’t. I’m so glad that I was part of this. It helps to talk to a therapist and that no one will know what we talk about, to just go over my problems. I’ve done so much here, crying, screaming, saying curse words - it’s almost like being at confession.”

Activities—Mothers from both groups listed a variety of coping activities, such as: writing down information and questions discussed with the medical team, taking walks, watching TV, crying, following as much of a routine as possible, and planning activities with family and friends. A European-American mother discussed how helpful it was to have routine and a sense of familiarity for their inpatient stays:

“It’s wonderful. We’ve had the best time we’ve had since we’ve been here. You get a routine. You know what you have to get down the hall, where there are blankets, when to talk to the nurses, you know who to do this with and that with. You settle in. You know where you have to go, what you have to do. And, somehow in the knowledge of that, you feel comfortable. You don’t feel as in the dark on things. You feel like if something comes up, you’ll deal with it.”

One Latina mother said that simply taking time to watch TV was helpful:

“Well, I’d lay down on the bed and I’d watch a TV program, not listening to my family asking for me to do things. I’d watch for just 30 minutes and I felt better.”

European-American mothers discussed additional activities, including: yoga, eating comfort food, relaxation exercises, consciously planning to think of positive thoughts for 15 minutes each hour, and pursuing fund raising for their child’s medical care. For both groups, coping

strategies included a mix of adaptive and potentially maladaptive activities. One of the European-American mothers talked about giving herself permission to eat what she'd like:

"What I did was, it sounds terrible, I went out and bought all kinds of snacks. I didn't care if it was fattening because I said, during this time, I don't care about gaining weight. I said, these foods make me smile and make me happy when I'm eating them and I'm going to do that while we're going through this and then after I'll go on my diet and lose it all back. Right now, when I feel sad and I want to eat an ice cream cone, I'm going to eat it. No guilt. It's happiness."

Latina mothers also had several other coping activities, including: listening to music, getting a manicure, dancing, taking naps, using humor, going to the beach, smoking, and getting massages. A Latina mother described an evening visiting cousins when she focused on trying to enjoy herself:

"I was with my sister and cousins. I went out and took out a cigarette and sat down. Today, I said, I want to be myself. Not any other day, but today. I said I wanted to dance and we put on music and we were dancing!"

Cognitive Coping Strategies

Problem solving—A common coping skill among all of the mothers was problem solving, which reflected the intervention model of the study. They discussed problem solving by brainstorming, weighing options, remembering past solutions, evaluating outcomes, and continuing to try other options. A European-American mother said:

"I remember the problems that I went through. You know, a lot of times I'll have a problem and I'll just get that problem out and I'll resolve it, but I won't forget, because that's also part of me helping with the next problem."

Similarly, a Latina mother explained:

"I have to look at what are all the possibilities of what I can do and select one, and keep trying. With the biggest or the smallest thing, you can look for solutions. It's the details you have to look at and see that you're not going to be stuck with the same problems."

The mothers discussed using their problem-solving skills not only in the medical setting but also with family members and school personnel. One of the European-American mothers talked about generalizing the strategies to her work setting. A Latina mother said she wanted to share the problem-solving worksheets:

"I told my husband that I'm going to save it all because it's in Spanish and that's something we can take to Mexico to help people because they don't have anything like this there and it can help people there, too."

Positive thinking—Both groups of mothers discussed positive thinking, optimism, and positive self-talk, which was also part of the study intervention. Mothers discussed building their own sense of self-worth, as well as feeling greater self-efficacy and ability to handle situations over the course of the study. One Latina mother said:

"I know now I can do it – I have a feeling of peace to know I can do it."

Another Latina mother provided an image parallel to the Bright IDEAS light bulb graphic that was part of the intervention model:

"Like a lighthouse sends a light. That means that there is a solution, that there is a way out."

A European-American mother discussed how she remained optimistic when her husband was talking about the possibility of their child's death:

"It was hard at first because all he could think about was planning the funeral arrangements, thinking about Christmases without her, facing birthdays without her. I was like, that's not happening, that's not even an option. He said, you have to think realistic and I was like, oh no I don't. I said, I can be optimistic; I'm not going to be realistic. There is a 40 or 60 percent chance or whatever in our favor; however you want to look at it, from whatever studies. I said we're going to be in that percentage. We're going to do everything we can from Western medicine and nontraditional if we have to. We will be fine either way and get through this."

Present orientation—All of the mothers talked of trying to maintain a present orientation by living in the moment and taking one day at a time. They also expressed wanting to try to enjoy each moment. One of the Latina mothers said:

"Just getting through hour by hour, it all gets better with time. So I always think that way, today, today, today."

Similarly, a European-American mother stated:

"We're just plugging along, taking it one day at a time."

Reframing—Another common theme among all of the mothers was reframing. They talked about trying to focus on positive aspects of their experience, including: receiving high quality medical care, becoming closer as a family, personal growth, and seeing family conflict in terms of their shared stress. They also discussed trying to make the best of the situation. A European-American mother explained:

"I wish this hadn't happened to us, but it's made us get closer as a family. Life is not perfect: it's what you make of it that makes it good."

One of the Latina mothers described the changes in her perspective on medical appointments over time:

"Before it was like a nightmare. I was so scared at first - with such desperation that I almost went crazy. Now I'm hoping each time it's going to be good news. I used to think going to the clinic was something negative, but now even if I don't get good news, I'm calm. I don't think the most drastic thing is going to happen anymore."

Avoidance—Both groups of mothers described themes of avoidance and escape in a variety of ways, including: not wanting to think about their child's diagnosis, wanting to leave the situation, experiencing feelings of unreality, and needing to go away. One European-American mother simply said:

"Sometimes you don't want to have to think."

A Latina mother said she gambles in Las Vegas as an escape:

"I go to Vegas, to the machines, and it's like therapy for me to be there, I forget all of this."

Religion—Mothers in both groups included religious themes as part of their coping. Mothers identified their spirituality as a source of support through prayer, as a concrete symbol (e.g., depictions of Catholic saints or pictures of a church building) for patients to focus on during medical procedures, a sense of a divine plan, God communicating with them, and in explanations to patients about their treatment. A European-American mother said:

“I can’t be there 24 hours a day, so I said, God, you have to be there, because I can’t. There’s no way...my worry doesn’t change anything. So, I have to give it to God. So, that’s how you get through it and you have incredible support.”

Similarly, a Latina mother stated:

“My son’s life is in God’s hands. I pray to God, I say lots of prayers for my son and this has given me peace. I feel like an avocado, protected from all sides. God helps so much.”

European-American mothers also discussed their church providing financial support to their family, having the patient’s siblings participate in the children’s church programs, and receiving support from their church friendships. Latina mothers talked about a variety of ways of feeling connected to God through how they interpreted events, sensed angels, felt the support of deceased family members helping them, and saw meaning in dreams. One Latina mother described it this way:

“I had a dream before about dirty water that I was using to clean my dry eyes. And this is true, it’s also what my sister in Guatemala was saying, to pray to God because if you dream of dirty water that means only sickness. And it was that next day that my daughter had the bad reaction to her chemotherapy. God was talking to me in my dreams. So I knew I had to be strong and I prayed. Last night I was dreaming of clear water, I was back in the town I’m from in Guatemala. There was clear water and today they told me my daughter is doing well, thanks to God.”

Mothers also expressed questioning and feeling angry with God for the patient’s illness. A Latina mother explained:

“I stay awake at nights thinking of everything and I ask God, why did this suffering come to us? My faith has helped me a lot, but sometimes it’s not enough.”

Compromise—A theme that was unique to the European-American mothers was seeking to compromise with the medical team. They discussed negotiating and finding middle ground about the patient’s treatment, as well as general hospital regulations. While both groups of mothers expressed some feelings of doubt and anger with the medical team, Latina mothers did not discuss attempts to compromise and seemed to generally follow the medical team’s instructions and treatment plans. In contrast, European-American mothers talked about trying to stay calm and listening to the medical team. One European-American mother stated:

“It’s kind of like you feel like you’re fighting against the team’s decision, but by the same token, you still want to meet in the middle. As long as the medical team can make me feel confident in the compromise, you know, I’ve got to feel confident in this.”

Perspective taking—Latina mothers, but not European-American mothers discussed trying to take the perspective of members of the medical team working with their child and their empathy with the medical staff, acknowledging that staff also have personal problems. One of the Latina mothers said:

“I try to understand the nurses, well, I put myself in their shoes.”

Another Latina mother said:

“I try to understand why these decisions are made from the doctors’ view and sometimes it works out better.”

Normalization—Another theme that was discussed among the Latina mothers was normalization. They often talked about the support they felt in getting to know other mothers going through similar experiences and providing each other with advice. European-American mothers discussed several sources of support, generally outside the hospital setting, and did not mention using normalization as a coping mechanism. One Latina mother said:

“There are a lot of us going through the same thing. We’re shut up in the rooms and we don’t have anyone else to talk to, so we meet each other. When I feel bad, sometimes I talk to the other mothers. We help each other.”

Discussion

This study employed qualitative analysis to identify and compare coping strategies among Latina and European-American mothers of children with cancer. Twelve coping themes were found from the text of the 24 sessions analyzed. Consistent with previous qualitative studies of parents’ experiences with their child’s cancer (Clarke & Fletcher, 2003; Ward-Smith, Kirk, Hetherington, & Hubble, 2005), mothers discussed gathering information about their child’s diagnosis and treatment and several sources of support, including professional help-seeking and religion. In addition, both groups of mothers discussed a variety of concrete coping activities, problem solving, positive thinking, present orientation, reframing, and avoidance.

There were variations by cultural group among the themes that were held in common. For example, Latina mothers reported gathering information from other families with children with cancer and difficulties accessing materials in Spanish, while European-American mothers relied on hospital resources and cancer webpages. Religion was part of both groups’ coping, but only European-American mothers discussed receiving financial and material support from their churches. There were also differences in the specific coping activities the mothers identified with European-American mothers using relaxation exercises, yoga, and planning on thinking positively each hour and Latina mothers describing more active coping behaviors like dancing, going to the beach, and using humor.

A theme that was unique to the European-American mothers was seeking to compromise and negotiate with the medical team as a way to try to obtain the result they were seeking, such as an exception to a hospital policy for their family. In contrast, Latina mothers discussed feeling empathy and taking the perspective of the medical team. Another variation in themes was the high importance placed on the support and normalization the Latina mothers sought from others going through similar experiences. While European-American mothers did discuss seeking support, it was generally through existing support networks outside of the hospital with people who did not have a child with cancer.

These differences between the two groups may reflect the cultural value of *simpatía*. *Simpatía* encompasses the cultural beliefs of *personalismo*, dignity, and respect identified by Andrés-Hymen and colleagues (2006) as considerations when providing services to Latinos. Marín and Marín (1991) explained: “*Simpatía* emphasizes the need for behaviors that promote smooth and pleasant social relationships. As a script, *simpatía* moves the individual to show a certain level of conformity and empathy for the feelings of other people. In addition, a person with *simpatía* (“*simpatico*”) behaves with dignity and respect toward others” (p. 12).

The results of this study suggest that *simpatía*, may be a central cultural value for pediatric oncology professionals to consider when working with Latino families. *Simpatía* might help Latino families cope with their child’s cancer through seeking support from each other and having positive and empathic perceptions of health care providers. *Simpatía*, in combination with language barriers and deference to authority, may also contribute to Latino families agreeing with and conforming to medical team goals without expressing possible doubts or

asking questions. For example, Nápoles-Springer and colleagues (2005) reported “Latinos tended to view themselves as too submissive” (p. 12). Culturally competent services for health care providers based on the findings related to *simpatía* include: mirroring empathy demonstrated by Latino families, frequently encouraging families to ask questions, normalizing their voicing areas of concern regarding their child’s medical treatment, and providing additional time for families to become more confident in directly expressing apprehension or disagreement (e.g., Andrés-Hymen, et al., 2006). In addition, rather than assuming that a family that has not requested an interpreter does not in fact need one or relying on family members to interpret, it is the responsibility of the medical team to ensure that information and services are provided in Spanish through use of trained interpreters or bilingual professionals (Sharma & Kerl, 2002).

Latina mothers also discussed how they benefited from training in cognitive coping skills, such as problem solving, positive thinking, and reframing, indicating that individual or group bilingual workshops in these coping skills should be considered in pediatric oncology centers. The results also suggest that medical teams need to be aware of the critical importance of support Latina mothers provide to each other. However, along with this shared support is the possibility of shared stress and communication of misinformation. Support among Latina mothers coping with cancer could be fostered by providing structured group interactions that include a bilingual health care professional to address questions and clarify potential misinformation.

While the small sample size limits generalizability, the purpose of the qualitative design of this study was to obtain more detailed information about coping in Latina and European-American mothers of children with cancer. Rather than asking the mothers directly about their coping strategies, this information was gathered from sessions focused on teaching problem solving for another study. Thus, these remarks reflect a rich source of real-time thoughts and behaviors for analysis (e.g., Polkinghorne, 2005). The initial findings of this study should be further investigated through quantitative measures of coping skills and cultural beliefs in larger representative samples of families coping with cancer. It should also be noted that both groups expressed appreciation for the problem-solving skills training provided through the study in which they participated. Future intervention studies should consider cultural adaptations that may better respond to the unique needs of various parental ethnicities. The high degree of cultural diversity within the United States mandates that health professionals within pediatric oncology aim to provide culturally competent care and conduct culturally informed research.

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Biographies

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