

Latino Caregiver Coping With Children's Chronic Health Conditions: An Integrative Literature Review

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ABSTRACT

In this study we examined research pertaining to how Latino caregivers cope with their children's chronic health conditions. An understanding of this topic could facilitate appropriate interventions by health care staff to promote optimal child health outcomes. In this integrative review we categorized 21 studies by publication characteristics, methodology, findings, and their focus on emotion-focused and/or problem-focused coping. Thirteen studies used a qualitative design. Five studies included fathers in the sample. Twelve studies investigated coping with child's asthma, primarily in Mexican or Puerto Rican families. Coping strategies utilizing religion/spirituality, alternate healing practices, family support, and education about the child's illness were identified. Language, cultural dissimilarities, receiving inadequate

information about the child's health care, differences in health beliefs, and feeling disrespected by providers were frequently cited coping challenges. Addressing these barriers is imperative to enhance coping of caregivers. Inconsistencies in research samples regarding income, education, immigration, and acculturation histories make findings difficult to generalize; recommendations for further research are suggested. *J Pediatr Health Care.* (2016) 30, 108-120.

KEY WORDS

Latino, Hispanic, caregiver coping, children, chronic health conditions

Parental coping and reactions to the stress of caring for a child with a chronic illness or condition depends on individual, family, and environmental factors such as understanding of the crisis event, problem-solving skills, and the family's resources, including financial, extended family structure, educational level, availability of social support, health beliefs, and spirituality (McCubbin & Patterson, 1983). Health and illness can be interpreted and explained in terms of personal experience and expectations. Through one's culture and ethnic background, one learns behaviors related to being healthy, recognizing illness, and even being sick (Spector, 2013). Cultural factors, family size, acculturation, and attitudes toward medical care differ for immigrant Latino families. Emerging literature examining the adjustment of Latino families who are coping with their children's illnesses suggests that racial and ethnic differences exist in the levels of burden experienced by families. For example, Latino parents of children with life-threatening illnesses were two and half times more likely to state that no one appreciated the burden of care they carried (Hinojosa et al., 2012).

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Coping is defined as an individual's response to stressful situations and involves psychological as well as cognitive resources and behavioral strategies that help to eliminate, modify, or manage stressful events or crisis situations (Lazarus & Folkman, 1984; McCubbin & Patterson, 1983). Children whose parents cope effectively with their child's illness show measured differences in health outcomes and recover earlier, whereas increased caregiver stress resulting from the demands of caring for a sick child is linked to negative health outcomes for the child (Duguid et al., 2007; McCubbin & Patterson, 1983). Because children are likely to recover faster when parents exhibit less stress, parental adaptive coping strategies should be routinely examined, and efforts to facilitate their coping should become an important role for all health care team members. The current study seeks to add to the existing literature regarding immigrant Latino parents' coping and caregiving experiences when raising a child with an illness or other chronic condition.

Latinos are the largest and fastest growing minority population in the United States, making up 15% of the nation's total population (Lynch & Hanson, 2011). Mexicans and Puerto Ricans are the two largest Latino subgroups (Hildebrand, Phenice, Gray, & Hines, 2008). The U.S. Census Bureau defines a Hispanic or Latino as a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (Ennis, Rios-Vargas, & Albert, 2011).

In 2010, there were 19 million Latino children younger than 18 years in the United States, constituting about 26% of the total number of children in the country (Waldman & Perlman, 2011). In the 2004 National Survey of Children with Special Healthcare Needs, 8.4% of Latino children, compared with 15.3% of non-Latino children, were reported by parents to have special health care needs (Waldman & Perlman, 2011). It is believed that the number is higher though, and according to Waldman and Perlman (2011), parents of Latino children, especially those from Spanish-speaking households, may be less likely to report health problems or seek health care for their children, and thus many illnesses are undiagnosed and untreated among Latino children.

Although Latino subgroups are similar in many ways (e.g., in their use of the Spanish language, in their religious beliefs, and in their health care experiences), they are diverse in their different points of national origin, immigration history, experiences with discrimination, acculturation, culture, and social class backgrounds (Hinojosa et al., 2012). As Latino groups migrate to different parts of the world, such as the United States, they are forced to acculturate to the new region, which can add to their stress, and their differences in beliefs can affect health, health behaviors, and access to health care (Hinojosa et al., 2012).

Health care providers also are socialized into the culture of their profession (e.g., doctors, nurse practi-

tioners, and nurses) and have their own set of beliefs, practices, norms, rituals, likes, dislikes, and myths; they adhere generally to the modern allopathic system of health care delivery, and with few exceptions, they fail to recognize or use any sources of treatment or medication other than those considered useful by scientific methods (Spector, 2013). When these health care providers encounter Latino families who may have different beliefs regarding their child's health and illness, unless the providers are culturally competent and try to understand the complex intersections of cultural factors related to Hispanic folk illnesses and the U.S. biomedical belief systems, it is likely that a barrier of misunderstanding might arise between the two, leading to a communication breakdown, and generally the consumer is disadvantaged (Andrews, Ybarra, & Matthews, 2013; Spector, 2013).

To appreciate this important issue, consider the case in which a U.S. hospital's surveillance video recorded a Mexican mother taking her 11-year-old daughter who was being treated for leukemia out of the hospital against medical advice. The family fled with the sick child to Mexico to continue her health care treatment in their native country. The mother expressed concerns that the child had complications from a hospital-acquired infection that had required right arm amputation and reported that the family felt intimidated by the hospital bills (Skoloff & Christie, 2012). This case captured media attention in 2012 and exemplified how lack of communication and trust, as well as financial burden, can affect a Latino child and family's health care experience. In a subsequent NBC news media interview on December 12, 2012, the mother reported that the child was happy, safe, and getting better under the care of doctors in Mexico, and that she did not bring her daughter to Mexico to die; this sentiment was corroborated by the child (Flam, 2012). The parents, for whom the health and well-being of their child was their primary concern, likely faced child endangerment charges in the United States because of their history of removing the child from a hospital against medical advice (Flam, 2012). Although this case may be a glaring example of cultural misunderstanding and highlights the lack of mutual trust and communication barriers between Latino parents and the U.S. health care systems, it is possible that if similar cases of misunderstanding with Latino families arose, the situations could be better managed if health care providers were more informed regarding how Latino parents cope with and manage their children's illnesses.

BACKGROUND

Latino Health Care Beliefs and Practices

Just as Latinos are diverse in certain cultural conventions, they are diverse in their health care beliefs. Most Latino immigrants in the United States access and receive health-related services in the conventional

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