# Fathers are Caregivers Too: Shifting Focus on Research with Latino Men Noe Mojica, LCSW

#### Abstract

This article presents a description of the state of knowledge about Latino fathers' coping with pediatric cancer and explains the need to shift the attention for research and practice with this group. In order to provide a fuller understanding of the fathers' experience, those conducting research need to analyze constructions of masculinity and move away from stereotypical models about men and their caregiving. The author proposes decentering research from the Anglo-American dominant focus and being more inclusive of other perspectives. Paths for inquiry to promote culturally sensitive interventions and research recommendations are provided.

Keywords: cancer, Latinos, fathering, caregiving, research

During years of practice as a social worker in the healthcare system, I have witnessed the challenges many families face when their children suffer a life-threatening illness like cancer. Statistics from the American Cancer Society (2015) indicate cancer survival rates among children have greatly improved compared to previous decades with overall survival approximating 83%. Some children with certain cancer diagnoses approach or exceed 90% long-term survival. However, an estimated 1,250 cancer deaths are expected to occur among children 0 to 14 years of age in 2015.

Parents may experience a sense of loss when they bring their children to the hospital because of the fact that illness presents the reality of their child's vulnerability and the caregivers' inability to alleviate the problem. A cancer diagnosis is one that places new burdens on the life routine of men. It may lead them to question notions they previously had about what it means to be a father and how they construe their masculinity.

I work predominantly with mothers from a wide variety of racial and ethnic backgrounds. About one quarter of these women are Latinas. The mothers' presence is more evident as they are often the ones who provide care to their children when hospitalized. I have also noticed a number of Latino fathers present, sometimes by themselves while their wives are at home or taking care of other responsibilities. The capacity of these men to dedicate their time and undertake a role that is usually associated with women is appealing to me. On the other hand, there is a larger number of fathers who are not present at the hospital. Their level of involvement, time, and effort to their ill children is less obvious. They seem to be invisible because they are rarely at the bedside.

This article presents a description of the state of knowledge about fathers' coping with pediatric cancer. More specifically, it discusses the need to take a new approach for research and practice with Latino fathers in order to provide a fuller understanding of their experience. To accomplish this, it is imperative to analyze constructions of masculinity and move away from stereotypical models about men and their caregiving. It includes decentering research from an Anglo-American dominant focus and moving towards increasing the inclusion of more ethnic minority groups, specifically Latino men, and bringing them out of the apparent invisibility.

## **Challenges of Fathers**

Researchers argue that social conditions have presented many challenges to fathers to assume an increasingly active role in raising children (White, Roosa, Weaver & Nair, 2009). The emergence of the feminist movement has questioned traditional gender roles and a redefinition of fathering (Silverstein, 1996; Dowd, 2000). This, in turn, has modified the distribution of parental responsibilities which, in the past, was based on the traditional roles of the mother caring for the children and the father functioning as provider (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000; Falicov, 2010). There is evidence suggesting an increased overall involvement from men. Their roles and behaviors at home seem to be changing from traditional norms to more gender egalitarianism (Coltrane, Park & Adams, 2004; Doucet, 2004; Pelchat, Lefebvre & Levert, 2007, Falicov, 2010; Galinsky, Aumann & Bond, 2011).

Saracho and Spoked (2008) compared fathers to "family ghosts" in relation to their children's development and well-being. They explain that the father's role is very often attributed to the financial support of his children. They seem to be "invisible" in other aspects of their children's lives. The few studies that have examined fathers' involvement in their children's lives may have created the perception that fathers were the "hidden parents." Some researchers indicate that given these family, social, and cultural variations and expectations, it is still largely true that those working in pediatrics seldom get to know the fathers as well as they do mothers (Coleman, Garfield & Committee on Psychosocial Aspects of Child and Family Health, 2004).

## **Constructions of Masculinity**

Earlier literature pictured Latino families with a certain pathology and social deficit view in which men are stereotypically autocratic. Accordingly, Latino men were seen as machos, regardless of country of origin, education, class, age or gender role beliefs (Mirandé, 1997). It is very important to be aware that Latino masculinities and gender identities should not be conceptualized as subordinate/marginalized but as complex and diverse as those of Euro-American men (Mirandé, 1997) and shaped according to social context (Levant et al., 2003). However, these shifts do not occur in a homogeneous, formulaic way. The changes happen unevenly and result in contradictory combinations in everyday life where some historical aspects of machismo coexist with increased egalitarianism (Gonzalez-Lopez, 2005; Maciel, Van Putten, & Knudson-Martin, 2009; Falicov, 2010).

New interpretations of how machismo is expressed are emerging (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008; Glass & Owen, 2010). In relation to Latino men they do perform roles that include loving husband, consumed father, family man, and provider for the family. Coltrane, Parke, and Adams (2004) in a sample of participants of low-income Mexican-American families suggest a complex portrait of father involvement. Fathers in the study were more involved in both masculine-typed and feminine-typed interactions with their children than their White counterparts. The authors suggest that this finding provides support for Mirandé's (1997) suggestion that Mexican men are labeled by the majority culture as macho and uninvolved in family life, "when in fact they often exhibit high levels of commitment to family and spend considerable time interacting with their children in nurturing and emotional ways"

(Coltrane, Parke & Adams, 2004, p. 185). The same study also found that men with more egalitarian ideals tended to be more involved in performing family duties.

Arciniega, Anderson, Tovar-Blank, and Tracey (2008) have made a distinction between traditional machismo and *caballerismo*. They conceptualized traditional machismo as focusing on individual power, hypermasculinity, aggressive behavior, sexism, and chauvinism, whereas caballerismo places emphasis on social responsibility and emotional connectedness (nurturing, family centeredness, and chivalry). The researchers found that traditional machismo was related to aggression and antisocial behavior, greater levels of what is called alexithymia (the degree to which one is not aware of affect). Thus, men who scored higher on traditional machismo had more difficulty being aware of and understanding their own and the emotions of others. This study's examinations are significant to help situate these scales into a larger and multifaceted model of masculinity.

Research emerging from Latin America has surpassed the notion of masculinity as monolithic. Various scholars propose a conceptualization of men constructing masculinities. They highlight the diversity of men's experiences and identities in opposition to an essentialist perspective which enfolds all men under a single identity (Ramírez, 1993; Shepard, 2001; Montesinos, 2005). Ethnographic work has explored how masculine identities manifest regionally according to geographic areas. Men act differently according to their setting. Those coming from rural areas conceive being men as closer to machismo, while men living in large developed urban settings reshape their masculine identities and advocate for more egalitarian gender relations (Viveros, 2001; Fuller, 2001; Valdéz & Olavarría, 1998; Olavarría, 2001). However, the same researchers have indicated that class differences of those living in urban areas also shape men's conceptions of their masculinity. Thus these researchers move beyond a reductionist conception of masculinity that is circumscribed to underdeveloped/rural macho mentality versus developed/urban flexible mentality (Hernández, 2007).

In light of this knowledge about masculinities, how do men cope when faced with pediatric cancer? One avenue to learn more, is taking a look to the area where most of the research has been done. These areas are coping differences and psychosocial functioning between men and women and their roles as caregivers.

#### **Psychosocial Functioning and Coping Differences of Mothers and Fathers**

Mothers tend to participate in more social-support seeking activities (Hoekstra-Weebers, Jaspers, Kamps and Klip (1999) while social support has a greater impact on means of coping for fathers when compared with mothers (Goldbeck, 2001). It is possible that fathers are more aware of or more concerned about the typical ups and downs of interacting with their children. They may be more vulnerable than mothers to perceived problems of interaction (Macias, Saylor, Haire, & Bell, 2007).

It has been reported that fathers primarily use solution-focused strategies of coping, whereas mothers tend to focus on emotions. This may mean that fathers do not have healthy outlets for expressing their emotions (Jones & Neil-Urban, 2003). They may be unprepared for the experience of grieving in addition to feelings of shame and embarrassment in relation to their

own needs for connection (Addis, 2011). A significantly greater proportion of fathers than mothers reported higher rates of depressive symptoms due to the child's health problems in research done by Bonner, Hardy, Willard, and Hutchinson (2007). In one qualitative study conducted by Wolff, Pak, Meeske, Worden, and Katz (2011), the most often cited challenges fathers reported included depressive symptoms, feeling alone and payment of expenses during the child's hospitalization.

Streisand, Kazak and Tercyak (2003) studied parenting stress related to caring for a child with cancer and family functioning outcomes (n=116). Results indicated that increased parenting stress was associated with poorer family functioning outcomes. The study also indicated that these families may need greater assistance in handling stress and in openly sharing responses with other family members.

Chesler and Parry (2001) in a sample of 167 men studied how fathers' experiences and stresses are influenced by gendered identities, gendered roles, and gendered organization of support systems. Fathers found it difficult to learn new skills and take on new chores. They experienced conflicting role obligations for work and family. Some fathers were not prepared for additional child care and housework. Although a number of men were willing to let their wives continue to perform those responsibilities, some fathers also felt they had to "fight" the mother to assume these tasks. Work was used to escape emotionally or practical demands. On an emotional level, men felt their role was to remain strong and not express emotions. They felt helpless and guilty for lack of control of the situation. They felt left out of the loop for medical information because the staff focused on the mother. Finally, the authors indicate that fathers had limited support from male friends. In light of these stressors, consideration needs to be provided to how fathers can cope effectively when facing pediatric cancer.

Protective factors, that is, the conditions or attributes in individuals and families that help them cope more effectively with stressful situations, are important to reduce risk. Brody and Simmons (2007) used the resiliency model of family stress, adjustment, and adaptation as a framework for exploring the resources assisting fathers adapt to life after their child was diagnosed. By using social supports in combination with constructive communication patterns, fathers were more likely to display resilient characteristics that enabled them to adjust to the changes in their family life. Fathers were very involved in the caretaking of the child. They reported that their relationships with family members were strengthened through the difficult times. They also valued healthcare professionals who were straightforward and honest with information sharing. The study indicates that fathers needed 3 important resources to emerge successfully from the pediatric cancer experience: good social support, strong communication skills, and an ability to adjust to the changes required of the illness. This is supported by other studies which indicate that the amount of support families receive (e.g., financial, emotional, and supportive) directly influences the caregiving response to a chronically ill child (Perrin, Lewkowicz, & Young, 2000; Hovey, 2006; Ygge & Arnetz, 2004). One study by Gannotti, Kaplan, Handwerker, and Groce (2004) compared service use, perceived unmet needs, and expectations of providers of Latino and Euro-American families. It found that Latino families were more likely to cite unmet needs in areas such as an unresolved health problem and need for more information or a support group.

In one literature review of articles published from 1992- 2002, Kerr, Harrison, Medves, and Tranmer (2004) looked into studies that addressed one or more of six supportive care needs (i.e., informational, emotional, psychosocial, practical, physical, and spiritual) in relation to parents of children with cancer. The main psychosocial need cited was for social support while spiritual and physical needs were cited in the fewer amounts of studies reviewed.

## **Integration of Latino Fathers in Research**

Cabrera and Garcia-Coll (2004) have expressed that little is known about what Latino fathers do as fathers. These authors have shown that Latino fathers continue to be studied from Anglo-American perspectives which omit language, beliefs, expectations, roles, culture, and aspirations. Fathering in the growing population of immigrants remains relatively unexplored (Capps, Bronte-Tinkew, & Horowitz, 2010). Immigrant fathers may face stressors such as unemployment, underemployment, language barriers, shifts in identity roles, and hurdles to services, all of which can have an impact on their parenting abilities. In addition, sociocultural beliefs about the roles and expectations of fathers may vary according to the norms in fathers' native country, leading to differences in parenting (Capps, Bronte-Tinkew, & Horowitz, 2010).

Most of the understanding about Latino fathers and their roles has been constructed by the writings of researchers who approached research on families from outside the families' cultural reality, using their own theoretical frameworks (Taylor & Behnke, 2005). As the United States becomes a more diverse society scholars have been stressing the importance of using various culturally appropriate methodological and theoretical paradigms to study ethnic minorities. This is a departure from Eurocentric perspectives and employing "cultural variance" or "ethnotheories" to study diverse families (Sherif-Trask & Marotz-Baden, 2007).

Coltrane, Parke, and Adams (2004) report that research on fathers' care of their children has focused on White, highly-educated, middle-class, intact families. Results from one meta-analysis on 29 studies examining psychological distress, marital, and family functioning among parents of children with cancer indicate the inclusion of Latino participants in this kind of research has ranged from minimal to completely absent (Pai et al.,2007). A total of 17 studies reported the ethnic distribution of the study sample. Participants were predominantly Caucasian (mean percentage of 83.92%). Hispanics in the sample ranged from 0% to only 8%. This is concerning in view of the increasing population growth and demographic projections of Hispanics in the United States in sharp contrast to the low level of inclusion in pediatric oncology research.

The literature review only resulted in few studies that focused on Latino males and their fathering. It was apparent that Latino fathers were included in some of the samples. However, their sampling totals were very small to make generalizations to the larger population. Approximately 58% of the study samples included in the study of Pai et al (2007) had fewer than 50 participants in each of the study groups. Small sample sizes may limit the power of the studies to find significant differences between groups. This could result in underestimating the influence of pediatric cancer on parents. Many of the studies relied on qualitative data gathering. There were only a few studies that included large samples of Latino fathers.

In summary, findings from the current literature review demonstrated that family functioning may be reduced at some point during the cancer course after children are diagnosed. The results of this review indicate that there is a growing number of studies addressing the impact of the diagnosis and treatment of childhood cancer on fathers which includes considerations to protective factors that help fathers and their families cope better. However, the amount of research on fathers' involvement constitutes a small fraction when compared with the amount of studies on mothers as caregivers. The number of studies is even smaller when considering research involving Latino fathers.

#### **Implications for Social Work Practice and Research**

Social workers are an important component in service provision in medical and other health care affiliated institutions where families and their children go to receive treatment or support services. Social workers are at the forefront of knowledge building and advocacy regarding marginalized populations such as immigrants, ethnic minorities, and the disabled. Social justice and inclusion are values rooted in the profession (Towle, 1965; Addams, 1990; National Association of Social Workers, 2008). These values shape practice and help to enhance the capacity of individuals, families, and communities so they can thrive and access better resources, improve quality of life, and transform their reality. The profession's principles of promoting change and social transformation are also relevant to the focus of this research as they relate to the pursuit of policy making relevant to the most important issues of society including healthcare.

The United States' healthcare system is undergoing a drastic transformation and the emerging challenges create policies and requirements that determine new priorities. There is the risk of shifting the attention to procedures, budgets and maximizing of profits leaving out the compassionate and dedicated care that centers on the vulnerable patient and family (Lown, Rosen & Marttila, 2011). Racial and ethnic minorities and persons living in increasingly economically disparate settings continue to suffer a disproportionate share of the cancer burden in the United States (Efird, 2013). In that regard, those professionals whose practice setting is the medical field need to assess their knowledge base and competence to engage in such a complex health care environment which promises to become more demanding and diversified as the shift in policies and regulations keep expanding (Efird, 2013).

The intersection of caregiving, masculinity and coping is a complex one that calls for further exploration in research in the context of healthcare. When the component of pediatric cancer is added to the equation, it becomes clear that in-depth inquiry is needed to have a wide perspective of the participants' worldviews, values and experiences. In light of that, mixed methods approach is a viable methodology when studying the topic (Greene, 2007). Mixed methods is a valuable methodology because it allows for collecting, analyzing and integrating both quantitative and qualitative data at some stage of the research process within a single study (Creswell & Plano Clark, 2007). More research is required to identify fathers' unique emotional, social, financial and health care roles and needs in family care giving. Longitudinal studies would also be valuable in capturing the experience of male caregiving over a specific timespan.

In addition, differences between particular subsets of the population such as patients with brain tumors vs. those with acute lymphoblastic leukemia needs further study. Differences in prognosis, as well as the types of treatment regimens, could have substantial implications for parents. Examination of the influence of child age on parent outcomes requires research as there is only a small number of studies (Pai et al., 2007).

It is also worth considering as well that despite their common-sense appeal, the familiar group labels habitually used in United States' health research are in fact based on a confusing mixture of characteristics, ranging from skin color to geographic origin to language preference. Differences are commonly ignored in health research, presuming homogeneity among people of diverse Hispanic origin. Researchers often use terms such a "Hispanic" to bundle all persons that includes over 400 million people from many different ethnic groups and subgroups, in more than 20 different countries (Hunt, Schneider & Comer, 2004).

Another aspect to highlight is that most of the research on fathers has been done from the optic of heterosexuality as the norm. Although it may be a challenging task to recruit gay participants, especially in the Latino community, it is obvious that there are same-sex couples (and gay fathers) caregiving for children with life-threatening illness. Gay fathers' perspectives would be valuable, "as they may also face additional stigmas in the health care systems that are not known to heterosexual fathers" (Wolff, Pak, Worden, Meeske, & Katz, 2010, p.215).

Finally, in developing interventions for this population, current recommendations suggest creating broad-based psychoeducational interventions that can be tailored to families' specific cancer experience (Torres, 1998) as well as narrative approaches to therapy in which men have the opportunity to have their voices and cultural stories heard (Torres, Solberg, & Carlstrom, 2002). More spaces are also needed for self-help and support groups (Chesler & Parry, 2001). However, the idea of a "support group" may be intimidating or unattractive to some men. Thus, interventions for fathers should be advertised as "information sessions," "workshops," or "seminars" that are more educational and explanatory initially (Wolff, Pak, Meeske, Worden & Katz, 2010). To summarize, a myriad of approaches has to be available.

#### Conclusion

The purpose of this article was to present a description of the state of knowledge about fathers' coping with pediatric cancer. Moreover, the goal was to present ideas about new approaches to research and practice with Latino fathers. Namely, an analysis of the constructions of masculinity and a challenge to move away from stereotypes was presented. Additionally, the literature review revealed that evidence indicates that gender identity has an important role in determining fathers' experiences and their ability to cope with their children's illness.

Researchers need to gain insight into the norms, expectations, and beliefs that determine Latino fathers' involvement and what constitute culturally appropriate father—child activities (Saracho & Spodek, 2008). The design of many studies created methodological challenges for researchers who attempted to learn about the nature and meaning of fathering in these groups. This was specifically noted when research is done with Mexican American families which constitute the majority of the Latino population (Cabrera et al., 2004; Coltrane, Parke, & Adams,

2004). Researching the lives of these men as caregivers becomes crucial in our efforts to gain a wider understanding of the challenges families face. This understanding is also linked to enhancing social work practice.

In closing, it is important to indicate that fatherhood in the growing Hispanic population remains relatively unexplored as a focus of research. Further, there are some studies, but limited to a small number that address the impact of the diagnosis and treatment of childhood cancer on fathers. These include considerations of protective factors that help fathers and their families cope better. Regarding parental involvement as caregivers, fathers only represent a small fraction of the focus of the literature, while mothers are heavily studied. This reality is indicative of stereotypical notions of men being relegated as secondary figures, and women considered the primary caregivers. This absence has further perpetuated the notion that fathers are invisible when it comes to the caregiving of children with life-threatening illnesses, such as cancer. Decentering research on fathering from the perspective of White, highly-educated, middle-class, intact families, will help social work engage in a more inclusive research endeavor to consider groups that have been historically excluded from the spotlight, thereby increasing the visibility of Latino fathers.

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