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LOYOLA UNIVERSITY CHICAGO

MEN AS CAREGIVERS: LATINO FATHERING OF CHILDREN WITH CANCER

A DISSERTATION SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

PROGRAM IN SOCIAL WORK

BY
NOE MOJICA

CHICAGO, IL
DECEMBER, 2016

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To the caregivers... you have such compassion for the most vulnerable.

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ABSTRACT

This study explored the relationships between Latino fathers' masculinity, caregiving and coping when faced with the demands of having a child diagnosed with cancer. Latino fathers of children receiving treatment for cancer at a pediatric hospital were interviewed using a questionnaire that provided quantitative and qualitative data for analysis. Results indicated no significant relationship between masculinity and caregiving or coping. However, conflicts between work, leisure and family relations were associated with an increase in the number of coping strategies used to deal with the stress of having a child with cancer. Themes from the qualitative data included fathers' role as providers, the connection with hospital staff and quality of care, tending to emotional needs, and maintaining hope and faith. The study's findings suggest an increasingly active role of Latino fathers in the care of their children and an emerging trend among these men to move away from the rigid roles that prescribe how a man must behave as it relates to coping and caregiving. Recommendations to support this population and guidance to those intervening in this area are provided.

Key words: fathering, cancer, caregiving, social support, coping, masculinity

CHAPTER ONE

INTRODUCTION

Background

This writer has been working as a social worker in the pediatric health care system for the last 11 years. During these years in practice, I have witnessed the challenges families face when their children suffer an illness. Parents experience stress and concern regardless of their children's sickness; it may be a common cold or a more serious diagnosis. Parents may feel a sense of loss when they bring their children to a hospital. Having a son or daughter who is ill presents the reality of the child's vulnerability and parents' inability to alleviate the problem. They come to the hospital looking for answers and with fear that things may develop in a different way than they hope. As a social worker, I feel honored to serve these families and provide a sense of safety and emotional support as they cope with uncertainties about what the future may bring.

I work predominantly with mothers from a wide variety of racial and ethnic backgrounds. About one quarter of them is Latinas. The mothers' presence is more evident as they are often the ones who provide care to their children when hospitalized or in the outpatient clinic. However, I have noticed many Latino fathers who are also present, sometimes by themselves while their wives are at home or taking care of other responsibilities. I ponder the capacity of these men to dedicate their time and undertake a

role that is usually associated with women. But I also consider the larger number of fathers who are not present at the hospital. They are also dedicating time and effort to their ill children in a less obvious manner. They may seem absent because they rarely show up at the bedside. I will elaborate more on fathers' invisibility and how this apparent absence has been constructed in the clinical literature. There seems to be a tendency to take for granted that women are primary caregivers while men are perceived as secondary figures (Jones, Pelletier, Decker, Barczyk, & Dungan, 2010). I'll discuss reasons why it is important to consider studying the fathers' role in contrast to the mothers'. In relation to that, it is imperative to analyze constructions of masculinity, moving away from stereotypical models about Latino men and the care they provide to children with cancer. In this case, a cancer diagnosis is one that places new burdens on the life routine of men. It may question notions they previously had about what it means to be a father as well as their own understanding of masculinity, and how that conceptualization may impede their openness to their own feelings.

I will discuss the need for de-centering of research on fathers from an Anglo-American dominant focus. The study seeks to contribute to more inclusion of the Latino perspective as underrepresented voices. It discusses relationships among variables of masculinity (independent variable) caregiving, coping and service seeking (dependent variables). The study seeks to add to the discussion with healthcare providers about work with culturally-diverse populations and enhance the understanding of factors contributing to caregiver's coping and the supporting them in this role.

Thus, the goals of this study are strongly connected with my interest in exploring the challenges of managing the competing demands that fatherhood places on men in the

Latino community. Studying the life of men as caregivers is an interest emerging from my aspiration to gain a wider understanding of the challenges families face. It also is linked to enhancing social work practice.

Influence of Social Work Principles

Social workers are an important component in service provision in medical and other health care affiliated institutions where families and their children receive treatment and supportive 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. Social work is a profession with a calling to share knowledge and expert insight with other allied professions working together in transdisciplinary settings. In addition, the tenets of social work encompass a broad perspective about human beings and their environment and the intricate and complex situations they face. Social workers advocate to find means and resources to overcome specific barriers to access adequate services. 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 and policy changes 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, professionals in the healthcare field is need to evaluate their knowledge base and competence to engage in such a complex health care environment that is becoming more demanding and diversified considering the rapid changes in policies and regulations (Efird, 2013). Providing a person-focused approach and healthcare environment that is sensitive to patients and their caregivers is essential for improved service quality. Social workers are educators and facilitators who are called upon to raise awareness and help facilitate change on behalf of underserved populations and to advocate for the direct care and support needed by their constituents (Strug & Mason, 2002).

Statement of the problem

Pediatric cancer is a serious illness that impacts many families today. Statistics indicate that about 10,380 children in the United States under the age of 15 will be diagnosed with cancer in 2016 (American Cancer Society, 2016). The most common cancers of children are: leukemia (cancer of the blood cells), brain and other central nervous system tumors, neuroblastoma (which forms in the nerve tissue), Wilms tumor (kidney cancer), lymphoma (including Hodgkin and non-Hodgkin and both related to

white blood cells), rhabdomyosarcoma (originating in the muscle tissue), retinoblastoma (eye tumor), and bone cancer (American Cancer Society, 2016).

Cancer treatment is a difficult process which affects children diagnosed with the illness as well as the family (Chesler & Parry, 2001; Kerr, Harrison, Medves, Tranmer, & Fitch, 2007; McGrath, 2001; Werner-Lin & Biank, 2006). In the United States, 30% of the adult population are caregivers and 3% are caring for a child with significant health issues. Out of the total number of caregivers 11% are Hispanic (Fox & Brenner, 2012). The demands placed on caregivers are varied and great, with the complexity of medical care continuing to increase. Caregivers are expected to take an active role in decision making related to treatment options, beginning during the diagnostic phase. Caregivers are expected to integrate medical information, learn new illness-related terminology, enter a new treatment setting, and find the time to accompany the patient to medical appointments (Honea, Brintnall, Given, Sherwood, Colao, Somers, & Northouse, 2008).

During hospitalization and treatment, caregivers play an important role in making decisions about care. The family often becomes the patient's advocate and primary decision maker. How well caregivers fulfill that role may be contingent upon their preexisting relationship with the patient, the family, the healthcare system, and their own sense of capacity for the role. Disagreement within the family about the most appropriate treatment options for the patient can cause excessive stress for both caregivers and patients, which result in reduced quality of life (Fried, Bradley, & Towle, 2003). Role adjustment difficulties and persistent psychological distress experienced by caregivers have been reported up to a year after patients have completed cancer treatment. Levels of

distress have been higher than those found in healthy controls (Mellon, Northouse, & Weiss, 2006).

Parents providing care struggle with a mixture of emotions which include grief, sadness, fear, isolation, and anger as they witness their children's experience of many medical interventions (Kerr et al., 2007; Werner-Lin & Biank, 2006). There is evidence that fathers' experiences related to their child's chronic illness are different from those of mothers (Gray, 2003; Neil-Urban & Jones, 2002; Pelchat, Lefebvre & Levert, 2007; Ware & Raval, 2007).

Social conditions have presented many challenges to fathers to assume an increasingly active role in raising children (White, Roosa, Weaver & Nair, 2009). Fathers with limited financial resources usually encounter multiple barriers to becoming involved with their children. These limitations include high rates of unemployment and joblessness, early childbearing outside of marriage, an incessant succession of negative life events, and a lack of positive male role models (Furstenberg, 1995).

The emergence of the feminist movement has questioned traditional gender roles and a redefinition of fathering (Dowd, 2000; Silverstein, 1996;). This, in turn, has modified the distribution of parental responsibilities which, in the past, were based on the traditional roles of the mother caring for the children and the father functioning as provider (Falicov, 2010).

There is evidence suggesting an increased overall involvement from men in their families and their roles and behaviors at home seem to be changing from traditional norms (Chesley, 2011; Coltrane, Park & Adams, 2004; Doucet, 2004; Falicov, 2010; Galinsky, Aumann & Bond, 2011; Pelchat, Lefebvre & Levert, 2007) Fathers often stated

that they are ambiguous about their roles as fathers (Fagan & Iglesias, 1999). Greater flexibility in the identity of the mother as the primary caregiver mainly for the child and the father as sole provider has enabled fathers to become more engaged with their children (Doucet, 2001). Family and community relations have shown a shift in the direction of gender egalitarianism; however, these shifts do not occur in a homogeneous, formulaic way. The changes are happening unevenly and result in contradictory combinations in everyday life where some historical aspects of machismo coexist with increased egalitarianism (Falicov, 2010; Gonzalez-Lopez, 2005; Maciel, Van Putten, & Knudson-Martin, 2009). However, there is research that indicates that disparities prevail regarding fathers' commitment to their children (Acker, 2006; Silverstein, 1996).

In addition to the wide range of variation in fathers' culture and expectations, there is a void in research related to documenting Latino fathers' experiences when providing care to children with cancer. It is significant to note that out of 29 studies examining psychological distress and marital and family functioning among parents of children with cancer only 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% (Pai et al., 2007). As these results indicate, the inclusion of Latino participants in this kind of research has ranged from minimal to completely absent. This is concerning when considering the increasing population growth and demographic projections of Hispanics in this country in sharp contrast to the low level of inclusion in pediatric oncology research.

Purpose of the study

Further study is greatly needed based on the importance of the Latino population and the level of knowledge that will be required to facilitate better service outcomes for this group. Men, including Latinos who are fathering children with cancer, can become an invisible group because they lack the exposure in research studies that mothers have (Coltrane, Parke, & Adams 2004; McNeill, 2007; Saracho & Spodek, 2008; Wiener, Vasquez & Battles, 2001). This void in research needs to be highlighted to sensitize health care professionals to their existence and to develop additional tools and competencies for professionals in the health care system, including social workers, nurses, and physicians. It calls for a deeper understanding of the father's role and position along the acceptance curve for the different challenges they confront having a child with cancer. Regardless of where they are in their coping, they deserve awareness and acknowledgement of the ways in which they support the child and the family during this extremely difficult time.

Although mothers usually assume the greater percentage of the day-to-day care of the child in Latino families, fathers are caregivers too, and therefore, deserve the respect and consideration experienced by their wives. Moving away from the stereotypical roles of the father as financial supporter, and sharing other possibilities of more roles for fathers suggests to the family that these roles are not competing with those of mothers. Further, a father's additional roles serve to support the overall needs of the family and make parenthood more satisfying for mothers and fathers (Coleman, Garfield, & Committee on Psychosocial Aspects of Child and Family Health, 2004). Culture plays an important role regarding expectations that fathers have when encountering the health care

system. A father from one family may have the cultural expectation to meet with the pediatrician and direct most conversations, while a father from a different cultural background may be expected to meet his child's pediatrician less frequently or never.

Pediatricians who understand parental expectations and the family's cultural traditions and values and who respectfully explore and encourage the father-child relationship are more likely to form a good connection with fathers and make them feel welcome. This in turn sends the message to fathers that they are important to their child's development and encourages them to be more active in the care and activities of their children. Encouragement from the child's physician can have a powerful effect on fathers and help them to expand their parental roles in their children's lives (Coleman, Garfield, & Committee on Psychosocial Aspects of Child and Family Health, 2004).

Research indicates that given the 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). Research has the potential to increase awareness of the importance of supporting and encouraging fathers' participation and their right to be included in medical conversations. Along those lines, the purpose of this research seeks to understand the intricate construction of various masculinities in the Latino population and how these intersect with the care men provide for their children with cancer. It hopes to contribute to an emerging body of knowledge in stark contrast to deficit models (Fitzpatrick et al., 1999) and stereotyped constructions of Latino family life (Lam, McHale, & Updegraff, 2012; McLoyd, Cauce, Takeuchi & Wilson, 2000) that do not seem to adequately capture the role Latino fathers as caregivers, or the level of

commitment and concern they have for their children. The study is geared towards the development of recommendations to assist in the creation of support systems to benefit Latino fathers with children diagnosed with cancer.

Theoretical Framework

There have been inadequate explanations of men's experience of their masculinity as presented in some of the psychological literature. On one end, psychodynamic theorists have described men's problems as a femininity complex, dread of women or a masculine protest and inferiority as noted in the writings of Boehm (1930), Horney (1932), and Adler (1936) and described by O'Neil (2008) in a summary of 25 years of research on men's gender role conflict. Freudian analysis focused on the repudiation of femininity. These concepts have highlighted psychoanalytic and unconscious dynamics of masculinity. They are in sharp contrast to the social constructionist perspectives of gender role strain and gender role conflict (O'Neil, 2008). This researcher gives preference to this theoretical approach because it integrates both the intrapsychic as well as the social factors which prescribe through implicit and explicit norms and expectations how men are supposed to perform as fathers and caregivers.

Masculinity is constructed differently depending on class, race, and ethnicity as well as by age and sexual orientation. Kimmel and Messner (1992) indicate that the resulting masculinities are complicated and have elements that cross-cut each other. They provide a word of caution against collapsing all masculinities into a single interpretation. New sociocultural conditions contribute in the construction of a new masculine identity (Montesinos, 2005; Ramirez, 1993).

This new masculinity adds to the complexity of the traditional notions that reproduce men's role as provider. In the past, male power depended on the capacity to economically sustain the family. Montesinos (2005) argues that this traditional role is subverted by social realities obligating men to be critical of their position and recognize women as equal. Thus, the role of employment in gender relations and the changes in the socio-economic forces contribute to a state of transformation in masculinity.

Rodriguez Cerda & Ambriz Bustos (2005) advocate for a transformational approach in which masculinity is interpreted as going through changes and diversification. This includes masculinities which are "modern", "traditional", "orthodox", and "heterodox". This construct includes a diversity of masculinities as part of the sociocultural reality and context. It is one in which patriarchal masculinity coexists with models of equality in gender relations (Rodriguez Cerda, & Ambriz Bustos, 2005). While those who strive for gender equality imagine a world in which gender norms are enforced effectively, it still leaves a world in which there are normatively backed expectations about the roles and characteristics of men.

Thus, in relation to expectations, gender role conflict theory (GRC) hypothesizes that rigid, restrictive, and sexist attitudes toward gender roles can cause negative consequences for men and others in multiple areas of life. GRC is assumed to occur at the cognitive, emotional, behavioral, and unconscious levels. It includes personal experiences of gender role restrictions. GRC has direct implications for men's and women's interpersonal, career, family, and health lives and can produce negative consequences for men personally and interpersonally (O'Neil, 2008). Furthermore, O'Neil (1981, p.62) hypothesized that, "men are also oppressed by a rigid sex role socialization process (i.e.,

sexism) that limits their potential to be fully functioning.” Thus, personal and institutional sexism and gender role conflict are shown as a predominant reality that shapes men’s lives. Sexism refers to attitudes, actions, or institutional structures that devalue, restrict, violate, or discriminate against an individual or group because of biological sex, sexual orientation, or gender roles. Sexism is the political, social, economic, and individual expression of a patriarchal system in women’s and men’s lives. The implication is that sexist structures in society and men’s gender role socialization are directly related to men’s GRC (O’Neil, 2008).

In addition, gender practices and beliefs and men’s role can be understood within a person-in environment perspective in which definitions and norms are socially constructed (Carter, 2014; McLoyd, Cauce, Takeuchi & Wilson, 2000) and influenced by social, political and cultural contexts (Lachance-Grzela & Bouchard, 2010; Lam, McHale, & Updegraff, 2012; Ridgeway, 2009; Thébaud, 2010). In that regard, fathering as an engendered identity and activity is viewed in opposition of a static reality. This means that gender identity as a construct is in dynamic transformation and evolution over the life span. To add to this definition, gender is constructed in everyday interchanges. Thus, behavior reflects the nature of the context and the burdens of the situation (Carter, 2014).

Thus, it is important to specify that gender is not a set of traits, a role, or a variable, but constituted through an ongoing activity embedded in human interaction. A person engaged in basically any activity may be held accountable for performing the activity as a man or a woman. These sex categories must be in tune with the respective gender prescribed behavior to be legitimated or discredited. Any activity is assessed as

falling into its womanly or manly constraints (Ridgeway & Correll, 2004; West & Zimmerman, 1987).

However, this researcher adopts a different theoretical approach that differs from the essentialist “men versus women” perspective about gender roles. An essentialist framework defines men and women as each having an unchanging “essence” and inclinations that are sex-specific (Heilmann, 2011; Newman, Fogarty, Makoae & Reavely, 2011). These universal attributes are independent of social context or culture. Essentialism is engaged in a commitment to preserve rather than diminish gender difference (Alcoff, 1988). The intention is not to demonize essentialism and disregard its importance in the development of a critique of sexism (Heyes, 1997). However, it is also worth acknowledging essentialism’s conceptualizations of gender which are devoid of historical, cultural and political contexts and the diversity of experiences of ethnic minorities. One way to understand the essentialist undertow is illustrated in the stereotyped depiction of Latino families as dominated by *marianismo*, which entails defining women as naturally emotional, self-giving and suffering for their children and *machismo* which regards men as naturally aggressive, tyrannical and stoic (McLoyd, Cauce, Takeuchi & Wilson, 2000; Torres, Solberg, & Carlstrom, 2002).

Therefore, when comparing women to men, an essentialist framework views the former as capable of a degree of physical and psychological intimacy with other human beings which exceeds men’s capacity to do the same. Accordingly, women place value on intimacy, develop a capacity for nurturance, and an ethic of care for the “other” through the development of connection (Gilligan, 1982; West, 1988). The essentialist explanation for women’s heightened sense of connection is that women are more “connected” to life

than are men because it is women who are the primary caregivers of young children (West, 1988). This essentialist framework has implications to the way caregiving is constructed as a gendered activity and centered around the role of women.

Domesticity is a gender system which holds the belief that women should have the burden of domestic responsibilities and childcare obligations. It arose around 1780 and by the turn of the nineteenth century this way of life was characterized by men's work in factories and offices while women (in theory) stayed at home to raise the children and tend "home sweet home" (Cunningham-Parmeter, 2015). The essentialist ideology of domesticity holds that men naturally belong in the market because they are competitive and aggressive, whereas women belong in the home because of their "natural" focus on relationships, children and an ethic of care (Williams, 2000).

Domesticity's description of women and men served to justify and perpetuate the housewife/breadwinner roles and established norms that specified optimal gender performance and the character traits suitable for these roles. One of the characteristics of this ideology was its organization of the market work around the ideal of a worker with a full-time job who takes little or no time off for the care of children. Although this ideal-worker norm does not extend to all jobs today, it does set the standards for many blue collar and professional jobs as well as executive positions for the middle class and above. However, when work is delimited in this way, caregivers are not able to perform as ideal workers. This gives rise to domesticity's marginalization of the caregivers by cutting them off from most of the social roles that provide responsibility and authority (Williams, 2000). Despite all the progress achieved by women and the breaking of barriers toward gender equality in the current twenty-first century, men in the United States continue to

be less involved in child caregiving and housework when compared to women (Galinsky, Aumann & Bond, 2011). Consequently, domesticity did not die but mutated (Cunningham-Parmeter, 2015; Williams, 2000).

Domesticity places a cultural expectation on all women to downgrade their market work and become the caregiving center of their families' lives once they have children. Thus, when it comes to equal share of responsibilities and caregiving in family life, it is easier for men to use their relative power to obtain a more favorable division of their household tasks. This is due to the low expectation for men's contribution to traditionally female tasks (Lachance-Grzela & Bouchard, 2010). However, one question raised from this in terms of men-women relationships with respect to the problem of gender is whether the goal should be gender equality or *genderlessness*.

The implication of enforcing gender equality is that the inequalities between men and women and gender role differences can be neutralized through various institutional devices. In contrast, the aspiration for genderlessness, is for the end of "normatively backed gender differentiation in social roles" (Wright, 2011, p. 409). The researcher deems important to explain that the possibility of a genderless society is not equivalent to a sexless society.

There would still be behaviors and dispositions that correspond to what we now view as feminine and masculine, and the mix of these would vary across persons. What would disappear is any systematic normative expectation that these traits and dispositions closely correspond to the distinction between males and females. And no costs would be associated with males and females having whatever pattern of 'masculine' and 'feminine' traits, dispositions and behaviors they might have. (Wright, 2011, p. 405)

Consequently, degendered family life and caregiving would mean that the norms related to family roles would be connected to parenthood instead of specific gender roles.

For example, in an opposite sex family there might be differences in relation to the mother or father taking on particular responsibilities because of differences in dispositions, preferences and limitations but there would be no normatively sanctioned expectations about who should do what (Wright, 2011).

However, the connection between women and caring for children remains entrenched in the culture. Women's adherence to this norm deemphasizes male-based caregiving in many ways. The call to nurture children causes some women to obstruct men's efforts to participate in caregiving by what is described as "gatekeeping." Whether they do this to preserve domestic power or to defend against male unskillfulness, gatekeepers control access to children by holding fathers to unrealistic expectations, monitoring them in their interactions with their children, redoing fathers' childcare work, or ridiculing these men for their caregiving "errors" (Cunningham-Parmeter, 2015).

Nevertheless, gatekeeping alone is not the central reason why men fail to engage in greater levels of caregiving. Instead, masculinities theory points to a group of norms that encourages men to distance themselves from anything deemed "womanly." This is exemplified by the language used when describing male caregiving in contrast to female caregiving. Thus, fathers who watch their children are described as "babysitters," while mothers who stay at home to care for their children are doing the "most important job in the world." In similar terms, popular discourse categorizes men who "show their feminine side" as honorary women. Thereby, this undermines the efforts to subvert masculine norms (Cunningham-Parmeter, 2015).

Because of the construction of caregiving as a gendered activity, the efforts are devalued and become invisible. Caregiving is further degraded when it is relegated to

those who lack economic, political, and social power and status (women, ethnic minorities, and immigrants). Thus, this devaluing contributes to the marginalization and dependency of caregivers (Glenn, 2000; Porter, 2011). For example, many caregivers have lives that make the full-time norm extremely difficult if not impossible. This strain places them in a disadvantaged position with their non-caregiver counterparts. Employers can treat them worse by either disciplining them for attendance violations or marginalize their careers in terms of work assignments, pay and promotions (Porter, 2011). Conversely, recognizing caregiving would raise the status and rewards of those who engage in it and increase the incentives for the larger society to engage in caring. Accordingly, “a society that values care and caring relationships would be not only nicer and kinder, but also more egalitarian and just” (Glenn, 2000, p. 84).

To attain a society in which caring is valued in all domains of social life, all the elements of caregiving and the people involved would have to be recognized and valued. Hence, the goal is one in which caring is recognized as "real work" and as a social contribution like other activities that are valued, such as paid work, military service, or community service regardless of whether the care provided takes place in the family environment or elsewhere. Those who need care including ill children are then recognized as full members of the society with corresponding rights (Glenn, 2000).

For these ideals to be achieved, there are specific conditions which must be fulfilled in the pursuit of equity and social justice. Thus, caregiving is legitimized as a collective responsibility rather than purely a family or private responsibility (Glenn, 2000). A communitarian framework which emphasizes on the priority of responsibilities, the importance of raising children well, and working together to reach a common goal

provides the needed justification for supporting wide transformation efforts aimed at ending the caregiver challenges. Caregivers are burdened on one hand with meeting their work schedules and on the other with setting time to meet the caregiving needs of their loved ones (Porter, 2010). The responsibility and actual work of caring would be shared so that the burden of caregiving does not fall disproportionately on women (Glenn, 2000).

However, parents should be respected and supported as caregivers regardless of the decisions they make in balancing work and family. Some families will choose that one parent does not work outside of the home whereas other families need both parents, or a single parent, to work full-time and sometimes overtime. In some families, the mother prefers more time with her family even though she may want to work. It is not so important that women are generally the primary caregivers or that sometimes they aren't and men are. What matters is stopping the punishing of caregivers for caregiving. The way to do this is by valuing caregiving regardless of who does it. In addition, it entails the right of caregivers to make the caregiving choices they feel most comfortable with (Porter, 2010). However, this does not ease the burden and stress that many caregivers must cope with.

Thus, the concept of coping can be traced back to research done related to stress and the psychological process experienced (Lazarus, 1966). Previously, most research on coping was geared toward concerns about pathology and depended on the evaluation of unconscious processes. Lazarus's work expanded the boundaries of coping to include a wider range of cognitive and behavioral responses that ordinary people use to manage distress of daily life. His theory placed a strong emphasis on the role of cognitive appraisal and how it shapes the quality of the individual's emotional response. The

framework was anchored on an understanding of a troubled person-environment relationship and the ways in which individuals coped with the appraised relationship (Folkman & Moskowitz, 2004). However, the current understanding of coping considers it as multidimensional and serving many different functions. Coping is used to solve external problems or to deal with one's own emotions to change the environment or to accommodate to it. It is used to engage in stressful interactions or to disengage from them.

In relation to a contextual approach to coping, Lazarus & Folkman (1984) state that coping processes are not inherently good or bad. Instead, the adaptive qualities of coping processes need to be assessed in the specific stressful environment in which they occur. Thus, a specific coping process may be effective in one situation but not in another. One determinant may be the level of control the person has over the situation. An additional consideration is that context is dynamic. This means that what may be deemed effective coping at the onset of a stressful situation may be considered ineffective later (Folkman & Moskowitz, 2004). Also, coping responses that are effective in relation to one outcome may have a negative impact on another. The emphasis is on obtaining the individual's own appraisal of the situation or condition in relation to a relevant dimension. The most frequently assessed dimension is the opportunity for personal control, or the appraisal of control (Folkman & Moskowitz, 2004).

In considering control, an additional aspect to consider is the assumption that a successful goal outcome involves mastery or resolution. It may be assumed that, for example, adaptive coping should lead to a permanent problem resolution and no further conflict or remaining outcomes while at the same time maintaining a positive emotional state. However, this approach seems to underestimate the chronic, unresolvable situations

and conditions that characterize the stress that many individuals experience when facing chronic illness and caregiving, grief and loss and which are very challenging in terms of coping (Folkman & Moskowitz, 2004).

Another aspect to consider is that coping involves both the physiological realm and the emotional assessment of the situation experienced. Expanding on this, coping is related regulation under stress and how individuals activate, manage, energize, and direct behavior, emotion, and orientation, under stressful circumstances. The focus is therefore, on forging links between coping and work on the regulation of basic physiological and psychological processes, which include emotion, behavior and cognition (Skinner & Zimmer-Gembeck, 2007). Emotion is integral to all phases of the coping process, from detection to vigilance, and the appraisals of threat during stressful encounters. However, it is important to note that adaptive coping does not rely exclusively on what are considered “positive emotions” or on inhibiting of emotional reactions. In any case, emotions such as anger have important adaptive functions because they help a person to prepare to confront or move away an obstacle (Skinner & Zimmer-Gembeck, 2007). Adaptive coping benefits from access to multiple emotions as well as the ongoing cooperation of emotions with other components of the action system (Holodynski & Friedlmeier 2006).

Finally, it is important to note two emerging areas in the discussion of coping. First, there is a departure from the individualistic approaches that focus on personal control, personal agency, and the individual’s direct action. Discussions of social aspects of coping include the impact of individual coping on social relationships and vice versa and the notion of communal, prosocial coping. The communal perspective refers to

coping responses that are influenced by and in reaction to the social context. Communal coping can include joining with others to deal with a situation together (Folkman & Moskowitz, 2004).

Second, religious coping has become one fertile area for theoretical consideration due to evidence about religion's role in the stress process and its influence on the ways in which individuals appraise events. People also use religion to help cope with the immediate demands of stressful events, especially to help find the strength to bear and to find purpose and meaning in circumstances that can challenge their most essential beliefs (Folkman & Moskowitz, 2004). One potential challenge is how to establish clear boundaries between concepts of religiosity and spirituality. Religious coping can include spiritual coping efforts to find meaning and purpose, or connect with a higher order or divine being that may or may not be religious (Mojica Sanchez, 2007; Folkman & Moskowitz, 2004).

In summary, based on the previous theoretical framework, fathering and caregiving roles are socially constructed definitions. Latino men's fathering and role as caregivers is explained within the historical, social, economic, and cultural context in which they live and perform their parenting tasks. In that regard, fathering as an engendered identity and activity is viewed in opposition of a static reality. This means that gender identity as a construct is in dynamic transformation. Gender role conflict theory hypothesizes that rigid, restrictive, and sexist attitudes toward gender roles can cause negative consequences for men as they are confronted by the demands and expectations from having a child with cancer. Masculinity is constructed based on gender stereotypes which limit men's capacity to elaborate a different identity that departs from

the static and traditional conceptions of what it means to be a man. Consequently, degendered family life and caregiving would mean that the norms related to family roles would be connected to parenthood instead of specific gender roles or associations of feminine versus masculine tasks. The demands on men who are caregivers of a child with cancer create a level of stress that is not easy to bear. Fathers' coping strategies are used to solve external problems or to deal with their own emotions and stressful situations to change the environment or to accommodate to it. A contextual approach to coping understands that coping processes are not inherently good or bad. Instead, the adaptive qualities of coping processes need to be assessed in the specific stressful environment in which they occur.

Definitions of Terms

The following is a list and explanation of concepts. This list is not exhaustive but it includes the main concepts under consideration.

Masculinity

This concept relates to gender relations and the practices through which men conduct gendered lives and the effect of these practices in bodily experience, personality and culture (Connell, 2005). Hegemonic masculinity refers to the dominant form of masculinity within the gender hierarchy. Dominant masculinities entail mechanisms regulated by culture, including the predominant way of thinking, and the ideologies that institutions support and legitimize about what it means to be a man (Connell, 2005).

Masculinity ideology and norms are primary values and standards that define, restrict, and shape men's lives. Masculinity ideology involves "the individual's endorsement and internalization of cultural belief systems about masculinity and male

gender, rooted in the structural relationships between the sexes” (Pleck, 1995, p. 19).

Gender role conflict (GRC) is a “cofactor” of masculinity ideology because restrictive gender role values can have negative consequences for men and jeopardize their interpersonal relationships (O’Neil, 2008).

Caregiving

Caregiving can be organized in a myriad of ways and can take place in the household or in publicly organized institutions, carried out individually or collectively and as paid or unpaid labor (Glenn, 2000). However, for the purpose of this study, caregiving is assistance provided by the father to the child diagnosed with cancer. Men become caregivers when they are called upon to assume responsibility for the physical and psychological/emotional needs of their children. In doing this, male caregivers may “experience changes in their expected and accustomed roles, behaviors, social or interpersonal relationships and perceptions about themselves” (Kramer, 2005, p. 7). In reviewing the literature on household labor, Sanchez & Kane (1996) point to a growing body of research which utilizes a relational or interactional theoretical approach with a focus on “individuals’ construction of themselves through relational, interactional labors such as housework and childcare” (p. 361).

Caregiving labors require attention to the physical, mental, social, and psychological needs and well-being of the child. Caregivers are expected to function broadly, provide direct care, assist with activities of daily living, emotional support, companionship, and medication supervision (National Alliance for Caregiving, 2004). They also undertake multiple responsibilities for tasks such as the following (Glajchen, 2009):

- Administrative tasks (management of insurance claims, bill payment).
- Instrumental tasks (cooking, cleaning, and other housekeeping tasks, accompanying the patient to medical appointments).
- Navigation tasks (seeking information that may be difficult to find).
- Social support activities (companionship, socializing).

Coping

Coping processes are the outward or inward efforts oriented toward adjusting to a child's chronic illness or condition (Broger & Zeni, 2011). It "consists of cognitive and behavioral efforts" to manage external or internal demands which are appraised as taxing or exceeding a person's resources. These efforts are continually changing as a function of appraisals and reappraisals of the person-environment relationship. Some of these changes in relationship result, in part, from coping processes geared at changing the situations causing distress (also known as problem-focused coping) or regulating distress (emotion-focused coping), from changes in the person that are a result of feedback about what has happened, and from changes in the environment independent of the person (Lazarus & Folkman, 1991).

Service Seeking / Social Support

This refers to the strategies that fathers use for accessing concrete resources for their mental and physical health while coping with a child who has cancer. This behavior is likely to enhance the lives of men and those who are close to them who may otherwise be negatively affected by the failure to seek support (Addis & Mahalik, 2003). Cultural, economic, and political systems as broader levels of context infuse different help-seeking

situations with meaning for men. Situations are perceived as threats depending in part on how masculinity is defined on particular contexts (Addis & Mahalik, 2003).

CHAPTER TWO

LITERATURE REVIEW

To accomplish the aims of this study, this chapter will review pertinent literature on Latino fathering and parental expectations. The chapter will also highlight research related to coping and illness. Since this study is centered on men as the target population, there will be an analysis of what studies suggest in relation to coping differences between mothers and fathers. This is done with the purpose of signaling the reasons why there is a need to focus on men's experience as distinct from women's methods of coping and obtaining support. Furthermore, this chapter will present research on masculinity as an important variable to consider and distinguish its definitions within the Latino population. In relation to this, a section will be dedicated to discuss the significance of gender identity in determining fathers' experiences and their ability to cope with their child's illness and treatment for cancer. Finally, the chapter will discuss how research on the construction of masculinity has evolved and the emerging new approaches to research on masculinity and Latino men. It will conclude with key points on how the literature relates to the purpose of this study, specifically, masculinity as the main variable and its relation to coping and caregiving.

What is Latino Fathering?

Saracho & 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. The few studies that have examined fathers’ involvement in their children’s lives may have created the perception that fathers were the “hidden parents.”

Research on fathers’ care of their children has focused on White, highly-educated, middle-class, intact families (Coltrane, Parke, & Adams, 2004). 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 that omit language, beliefs, expectations, roles, culture, and aspirations. 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 using “cultural variance” or “ethnotheories” to study diverse families (Sherif-Trask & Marotz-Baden, 2007).

Latino Parental Expectations

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). There have been problems with

conceptualizing fathers' involvement with their children in ethnically diverse and low income groups. 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 most the Latino population (Cabrera et al., 2004; Coltrane, Parke, & Adams, 2004). Fathering in the growing population of immigrants remains relatively unexplored (Capps, Bronte-Tinkew, & Horowitz, 2010). Immigrant fathers are also included in this underrepresented group.

Immigrant fathers may face stressors such as unemployment, underemployment, language barriers, discrimination and exploitation, 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 per the norms in fathers' native country, leading to differences in parenting as indicated in a study by Capps, Bronte-Tinkew, & Horowitz (2010) which included immigrant fathers of Mexican origin.

Research has also been done to consider the relationship of culture and expectations as they relate to the healthcare system. One study by Gannotti, Kaplan, Handwerker, & 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 the following areas: an unresolved health problem, rehabilitation therapy programs, and need for more information or a support group. The authors point out that Latino cultural values play a role in these differences.

These values create barriers for effectively communicating with providers and for meeting children's needs.

One additional area explored is the intersection of access to services and parents' use of information technology. Han & Belcher (2001) describe aspects of computer group as a vehicle for self-help by parents of children with cancer who had participated in online support groups (n=73; 55 mothers and 18 fathers in a convenience sample). A strong limitation of this study was that most participants were Caucasian, well educated, and of high socio-economic status. The perceived benefits of the computer group involvement included getting information, the sharing of experiences and venting of feelings, getting general support, gaining accessibility, and the use of writing. Disadvantages included negative emotions and large volume of mail. Participants also reported lack of physical contact and proximity.

Latinos go online from a mobile device (such as cellular phone) and use social networking sites at similar and sometimes higher rates when compared to other groups in the United States (Lopez, Gonzalez-Barrera, & Patten, 2013). Although more research is needed, the implementation of low-cost, online social media resources may be the best solution (particularly with younger generations) as virtual sources of support. It seems evident their influence may supersede ethnicity and gender barriers (Geana, Kimminau, & Greiner, 2011).

Coping: Moving Beyond a Pathological Framework

The past 35 years have seen a dramatic increase of coping research across social and behavioral science, and health related fields. Studies range from small-sample qualitative designs to large-scale population-based studies. The content has stretched

from the exploration of abstract theoretical aspects to applied studies in clinical settings. Earlier research and conceptualization was done in the framework of ego-psychology and the concept of defense (for example, Haan, 1969; and Menninger, 1963). This research was often focused on pathology and relied on the evaluation of unconscious processes (Folkman & Moskowitz, 2004). Vaillant (1977) organized the defenses into four levels. They ranged from the psychotic (denial of external reality, distortion, delusional projection) to immature ones (such as fantasy, projection, and passive-aggressive behavior) the neurotic (which included repression, reaction-formation, and intellectualization) and the mature mechanisms (sublimation, suppression, altruism, and humor). Vaillant (1977) used case studies to illustrate what he called the “adaptive style” that characterized the men he studied and how they managed their lives. One limitation of this research is that descriptions of coping styles that are based on case analysis tend to be individual portraits and they do not facilitate interpersonal comparisons and group analysis (Lazarus & Folkman, 1991).

Lazarus (1966) pioneering work expanded the boundaries of coping beyond defense and pathology to include a wider array of cognitive and behavioral responses that people use to manage distress and the problems of daily life related to it. Lazarus’s theory placed attention on the role of cognitive appraisal and how it shapes the quality of the individual’s emotional response. It also focused on the troubled person-environment relationship and the ways in which the people coped with the appraised relationship (Folkman & Moskowitz, 2004).

By the late 1970s publications included scholarly articles and books on adaptation and coping with illness (Antonovsky 1979; Moos & Tsu, 1977). By the early 1980s,

reports of empirical studies of coping began to appear in increasing numbers. Since then many new measures have been developed and numerous studies have been published (Somerfield & McCrae, 2000). Even though defense-focused research continued, psychological cognitive approaches prevailed (Folkman & Moskowitz, 2004).

Coping and Gender Identity

Chesler and Parry (2001) compiled data from different sources (e.g., workshops versus interviews at different time periods) and combined it into one data set. They used qualitative data from 167 fathers of children with cancer (no information about the racial-ethnic composition). The characteristics of the fathers in the sample varied tremendously. Some fathers had children still in treatment for cancer, some were bereaved, and others had children who had completed treatment and were longer term survivors. Results indicated that gender identity has an important role in determining fathers' experiences and their ability to cope with their children's illness. According to this study, the participants' identity as men defined the ways in which they dealt with the emotional and interpersonal stress of cancer. Many other participants who had strong feelings found it difficult to express them. Some of the men used "strong and silent" coping or emotional style in which they denied, ignored, covered up, or failed to express feelings of pain, sadness, and vulnerability. However, other men reported that the crisis touched them so deeply that they were compelled to challenge their traditional coping styles. In many cases, parents reported a division of labor consistent with traditional gender roles. Fathers focused on external employment and the provider role and mothers fulfilled the internal child care and household role (Chesler & Parry, 2001).

Coping Differences and Psychosocial Functioning Between Mothers and Fathers

Research has included an analysis of differences in psychological distress and coping styles between fathers and mothers. An early study suggested that fathers use more active-problem focusing at diagnosis and a less palliative reaction pattern than mothers. Mothers tend to participate in more social-support seeking activities (Hoekstra-Weebers, Jaspers, Kamps & Klip (1999) while social support has a greater impact on means of coping for fathers when compared with mothers (Goldbeck, 2001). An early study indicated this may be related to a relative lack of social supports and men's need to be in control (Longo & Bond, 1984). One study that compared stress levels among parents found that fathers reported significantly higher levels of stress from dysfunctional parent-child interaction (Macias, Saylor, Haire, & Bell, 2007). An earlier study consisting of a randomized sample of sixty-four families of children diagnosed with leukemia (no parental ethnicity specified), found that variables related to good coping were age of child, coping with other family members, occupational status of the father, and lack of sibling problems (Kupst, Schulman, Honig, Maurer, Morgan, & Fochtman, 1982). 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).

On the other hand, it has been reported that fathers primarily use problem-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). A study by Fragoso and Kashubek (2000) with Mexican-American men found that higher levels of machismo and restrictive emotionality were associated with stress and

depression. This study also found that restrictive emotionality and concerns with success, power and competition are predictors of men's stress.

For some men, it can be debilitating to cope with chronic illness of a family member. 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). One study examined the psychosocial functioning of a small sample of Caucasian and African American fathers (n=23) who identified themselves as taking the primary role in managing their child's health-related care. These fathers were compared to a matched sample of mothers who had also identified themselves as the primary medical caregiver of their ill child. Researchers found no differences between fathers and mothers across most measures of psychosocial functioning. However, both fathers and mothers indicated levels of self-reported psychological distress that were above normative means when results were examined and compared descriptively. In addition, a significantly greater proportion of fathers than mothers reported higher rates of depressive symptoms due to the child's health problems (Bonner, Hardy, Willard, & Hutchinson, 2007). Further concern is that compared to women, men are far less likely to seek treatment for themselves, and those who go to treatment are more likely to drop out prematurely (Addis & Mahalik, 2003). Additionally, research on men's gender roles has shown that gender role conflict was correlated with negative attitudes towards help seeking (Good, Dell, & Mintz, 1989; White, 2002). Thus, men may be unprepared for managing such emotions in response to the child's illness.

In a qualitative study with a group of Puerto Rican mothers whose children had cancer, women indicated that fathers initially demonstrated greater difficulty in accepting

the diagnosis (Rivero-Vergne, Berrios, & Romero, 2008). The sample was limited to 18 participants: 7 children, 7 mothers, 2 nurses and 2 oncologists. Participants interviewed described that during the process, most men were not able to express their feelings. On the other hand, a qualitative study conducted by Wolff, Pak, Meeske, Worden, & Katz (2011), indicated Latino fathers tended to be the most expressive about their own feelings when they were compared to participants from other racial/ethnic groups (n =15). This study used a life story method to explore the meanings of fathers' roles and beliefs that have developed based on experiences over the course of one's lifetime (with the use of semi-structured interviews). The most often cited challenges fathers reported included depressive symptoms, feeling alone and payment of expenses during child's hospitalization.

Caregiving and Parental Stress

There seem to be a multiplicity of factors to describe how men feel towards caregiving. The bulk of caregiver research to date has been conducted with older individuals living with conditions that are often associated with older age such as Alzheimer's Disease and related cognitive impairment as those who have suffered cardiac problems (Coe & Neufeld, 1999; Fuller-Jonap & Haley, 1995; Parsons, 1997; Baker & Robertson, 2008; Pierce, Steiner & Smelser, 2009; Sanders & Power, 2009; Baker, Robertson, & Connelly, 2010; Lin, Fee, & Wu, 2012), patients diagnosed with HIV/AIDS (Cadell, 2007; Munro & Edward, 2010) and functional or physical impairments (Campbell & Martin-Matthews, 2000; Ha, Hong, Seltzer, & Greenberg, 2008; Lin, Fee, & Wu, 2012).

Statistics from the American Cancer Society (2016) indicate cancer survival rates among children have greatly improved compared to previous decades with overall survival approximating 83% and some children with certain diseases approaching or exceeding 90% long-term survival. However, an estimated 1,250 cancer deaths are expected to occur among children 0 to 14 years of age in 2016 although it is important to note that mortality rates for pediatric cancer have declined by 67% over the past four decades from 6.3 per 100,000 in 1970 to 2.1 in 2011.

In that regards, hearing that a child has been diagnosed with cancer can be traumatic for his or her parents. Stuber, Kazak, Meeske, and Barakat (1998) suggested a trauma model for understanding how parents respond to such news. Parents must cope with continued events that extend far beyond initial diagnosis. These include time-consuming visits to the hospital and other health care facilities, painful treatments, and expensive medical procedures. Wolff, et al (2011) indicate that continuous re-experiencing of trauma by the patient and parents can lead to *pediatric medical traumatic stress* (PMTS).

There is growing research evidence supporting a traumatic stress model for understanding and addressing psychological reactions in relation to pediatric illness (Saxe, Vanderbilt, & Zuckerman, 2003). It is worth mentioning that PMTS is related to traumatic stress disorders like acute stress disorder and posttraumatic stress disorder (American Psychiatric Association, 2013). However, it is not limited to these diagnostic categories. The specific requirements of these diagnoses may not fit some of the parental reactions to medical events. Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke (2006) conceptualize PMTS as posttraumatic stress symptoms. It is a continuum

of key symptoms of PTSD (e.g., arousal, re-experiencing, avoidance) which may be present without meeting criteria for a full diagnosis of PTSD or ASD. For example, children with cancer undergo invasive medical procedures, endure pain, and may need to be admitted to the hospital repeatedly. Parents' anxiety during treatment and fearing that their child would die and worrying about relapse is related to later posttraumatic stress symptoms (Best, Streisand, Catania, & Kazak, 2002). In one study of 119 mothers and 52 fathers, all but one of the parents reported posttraumatic stress symptoms. One half of the fathers reported PMTS in the moderate to severe range (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005).

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

A literature review of research between 1980 and 2005 (Klassen et al, 2007) identified factors that have been investigated as explanations of variability in the well-being of parents of children with cancer found that certain child characteristics (e.g., child behavior; time since diagnosis) and indicators of coping (e.g., family cohesion, social support, stress management) are related to parental psychological health. Another

important finding was that parental self-perception, family-centered care, and physical health have received less research attention.

In another literature review of articles published from 1992- 2002, Kerr, Harrison, Medves, & 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. Forty-nine studies met the search search criteria. Twenty-five of the studies used quantitative methods, 20 used qualitative methods, and 4 used mixed methods. Informational (88%) and emotional (84%) needs were the most frequently identified. Support with finances was a highly recognized need. The main psychosocial need cited was for social support while spiritual and physical needs were cited in fewer amounts of the studies reviewed.

Another study (Martin et al., 2011) compared family functioning and coping styles within and between 2 different medical groups: families of children with cancer (n = 44) and HIV disease (n = 65). This study included a very small number of Latino participants (only 3 persons or 7% of the total sample). More reliance on social support was indicated among the cancer group. Also, the HIV group sought support from family, whereas both family and non-family support were sought among the cancer group. Results for this group were not segregated by race or ethnicity.

Reshaping the Image of Latino Fathers and Masculinities

Research supports an understanding of machismo as a kind of traditional masculinity ideology occurring in Latino men, which has potentially harmful effects for those who endorse it, and for others around them. There is also research which seems to support the assumption that Latino males may endorse greater levels of traditional

masculinity ideology than African Americans and European Americans (Abreu, Goodyear, Campos, & Newcomb, 2000). Earlier research (Cromwell & Ruiz, 1979) concluded that there was a “myth” regarding male dominance in Mexican and Chicano families when it comes to decision making among spouses. It pictured Latino families with a certain pathology and social deficit view in which men are stereotypically autocratic. Accordingly, Latino men were seen as macho, regardless of country of origin, education, class, age or gender role beliefs (Mirandé, 1997). Thus, Latino masculinities should not be conceptualized as subordinate/marginalized but as complex and varied as Euro-American masculinities (Mirandé, 2007) and shaped according to social context (Levant et al., 2003).

Mirandé (1997) has presented Latino men in a more positive light with a cadre of traits. These traits included courage, true bravery, generosity, and heroism. New interpretations of how machismo is expressed are emerging. Latino men do perform roles that include loving husband, consumed father, family man, and provider for the family. Coltrane, Parke, & 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 gender traditionalism (meaning strict gender-based roles) was

negatively associated with all components of father involvement. Men with more egalitarian ideals tended to be more involved in performing family duties.

Research emerging from Latin America has surpassed the notion of masculinity as monolithic. These researchers propose a conceptualization of men constructing masculinities, recognizing the diversity of men's experiences and identities departing from an essentialist perspective which encloses 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 conclusion, 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. However, this is a very small number when compared with the amount of research on mothers as caregivers. Very often studies will report combined outcome results for mothers and fathers without providing much emphasis on differences in issues faced by fathers. 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 generalize to the larger population. Many of these studies relied on qualitative data gathering. Studies that included large samples of Latinos fathers were few.

In relation to the main variables of this study, there are some points to summarize. Fathering in the growing population of immigrants remains relatively unexplored. Sociocultural beliefs about the roles and expectations of fathers may vary according to the norms in fathers' native country, leading to differences in parenting. In regards to coping, evidence indicates that gender identity has an important role in determining fathers' experiences and their ability to cope with their children's illness. Qualitative studies, although not generalizable, suggest that gender identity has an important role in determining fathers' experiences and their ability to cope with their children's illness. Many male participants who had strong feelings found it difficult to express them. Some of the men may rely on a coping style in which they do not show their vulnerabilities so they can conform to a traditional masculinity. Research indicates the main psychosocial need for parents coping with pediatric cancer is related to social support while spiritual and physical needs were cited in the fewer amounts of studies reviewed. However, this contrasts with some evidence that shows men tend to participate less in social-support seeking activities. Pertaining masculinity, there is research which seems to support the assumption that Latino males may endorse greater levels of traditional masculinity ideology when compared to other groups. There is also research that indicates gender traditionalism (meaning strict gender-based roles) is negatively associated with all components of father involvement in the lives of their children. Finally, men with more egalitarian ideas tend to be more involved in performing family duties.

Research Questions

This study will explore the masculine identity of Latino fathers, their caregiving role, and coping when a child has cancer. Thus, based on the limited amount of research in this area, the following questions have been elaborated:

- 1-What is the relationship between Latino fathers' masculinity and their caregiving activities?
- 2-What is the relationship between Latino fathers' masculinity and the ways in which they cope with pediatric illness?
- 3-How do Latino fathers define the tasks and responsibilities they have in their caregiving role?

The previous questions emerge from the premise that all men who will participate in the research have a definition of masculinity; that is, they can reflect on how they perceive themselves as men and the behaviors, responsibilities, and challenges associated with their role.

The main variables to be analyzed are masculinity (independent variable) and its effect on two dependent variables: caregiving role and coping. Thus, the research will explore men's concept and identity and how it relates to the tasks they perform when providing care to their children. It also seeks understanding about men's ways of engaging and managing the multiple stressors and challenges faced with their children and the means or instances where they can access support.

CHAPTER THREE

METHODS

Methodology Design

This study used quantitative methods with a questionnaire consisting of a set of three standardized scales to measure the main variables. Most of the questions were closed-ended. However, there were also a small number of qualitative questions to explore additional aspects of the caregiving experience. This study was exploratory because of the limited amount of research conducted with Latino men and their role as caregivers of children with chronic illness, specifically, those who have a cancer diagnosis. On the other hand, the use of correlations in the design of the study included measuring precise variables and their relationship with Latino men's self-report of their masculine identity. Thus, the methodology was designed to look at the relationships between the coping and caregiving due to the illness of the father's child and his perception of masculinity.

Data collection was cross sectional. This means that data was collected at one point in time. One limitation of the study was that the subjects' experiences were not all similar because of the diagnosis of their child. More specifically, those affected by chronic illness, specifically cancer, go through different phases in the evolution of the diagnosis and are at risk of a relapse. For example, some participants may be further away from the date of initial diagnosis while others may still have those moments fresh in their minds. The psychological stress experienced by the participants may vary based on

whether their children had recently experienced a crisis or relapse versus those whose children have been stabilized in their treatment or show minor symptoms. Another important limitation of a correlational design was that there are many other variables which may impact coping and caregiving besides masculinity.

Sampling and Recruitment of Participants

This study examined participants from one specialized, large pediatric hospital in a major urban area. Participants were Latino fathers of patients who were receiving services in the hospital at the time of recruitment. Fathers recruited for the study had a son or daughter who had been diagnosed with cancer and were either admitted into the hospital inpatient unit or those who were receiving treatment in the outpatient clinics. The researcher created a master list for the research which included the father's name, patient's name, address, and diagnosis to keep track of the recruitment process and meeting the sample quota as well as all meeting dates, times and location. The researcher was the only person using the master list which was well-kept in a locked cabinet. An electronic back up of the list was kept in a password-protected file in the computer network. The list of participants' names was shredded after sample quota was established and no more individuals were needed for recruitment. The electronic list was deleted as well.

Participants' ethnicity, address, diagnosis, date of diagnosis, and language spoken was determined using EpicCare. This is an integrated software suite to manage the electronic medical records with applications that support functions related to patient care such as registration and scheduling, and clinical systems for doctors, nurses, and other healthcare providers. Patient information was available in the socio-demographic section

of the patient's medical chart. EpicCare's usefulness was twofold. First, it helped to identify possible participants. Second, it was used as a tool to filter the candidates based on selection criteria.

Inclusion Criteria

The following was inclusion criteria for the study sample:

- Latino men who are fathering a child who is 18 years old or younger and diagnosed with cancer.
- Fathers' marital status: married, single, separated, divorced, widowed, or remarried, and fathers in cohabitating couples.
- Fathers' ethnic identity criteria was self-reported. This included any parent who identified as Latino/Hispanic, or migrating from Spanish-speaking Latin American countries. Participants were English and/or Spanish-speaking males.
- All fathers had to be 18 years of age or older.

Exclusion Criteria

- Fathers of newly diagnosed patients (< 3 months) were not included, as they may have had insufficient personal experience to fully discern what it meant to parent a child with cancer. Additionally, the author wanted to be sensitive to the time needed for families to process the initial sense of loss, stress and shock after a new diagnosis. A “dynamic nature of distress at time of diagnosis” makes it more challenging to recruit and retain participants (Stehl et al., 2009, p.811).
- Fathers who lived out of the state of Illinois were excluded.
- Fathers of children with a poor prognosis were not selected. This type of prognosis meant that the cancer was hard to control or was in a terminal state.

Board-certified physicians, advanced practice nurses, and social workers from the Hematology/Oncology department were consulted in ruling out those who were unsuitable to be interviewed. Fathers who were emotionally unstable were selected out to prevent psychological harm. This was determined by the feedback requested from the medical team or social worker.

Patients' current service status with the Hematology/Oncology Department was also checked using EpicCare to make sure the patient was receiving medical services related to the cancer diagnosis.

A total of 31 fathers met the previous selection criteria. However, eight of the fathers declined to participate in the study after the researcher discussed the purpose of the research. Some of the subjects indicated their reason to decline was not having available time for the interview, or conflict with work schedule. An additional father who met the criteria was later excluded because he was unable to be reached. One father was excluded because the patient's prognosis deteriorated. Another one was excluded because the patient had a relapse on the date when the father and the researcher were going to discuss the consent process. The final convenience sample consisted of 20 participants with a response rate of 65%. The sample size was decided in relation to the smaller number of Latino families seen in the hospital compared to other populations.

Measures/Instrumentation

The instrument was a questionnaire to measure masculinity as an independent variable and caregiving and coping as dependent variables. The questionnaire was a compilation of standardized measures of these variables. The first scale was the *Gender Conflict Scale*, also known as GRCS (O'Neil, Helms, Gable, David, & Wrightsman,

1986). The second scale, *The Care of My Child with Cancer* (Keegan Wells et al., 2002) was used to measure caregiving demands. The third was the *Ways of Coping* scale (Folkman & Lazarus, 1985) which was used to measure the fathers' coping. All the questions from the scales were closed-ended. Also, along with the standardized measure, a series of open-ended questions were included as a qualitative aspect. These were geared to explore (1) what fathers found most helpful during their stays or visits to the hospital, (2) their most important responsibilities in the family and (3) what they would like to tell other fathers. These questions were conceptualized and included after thoughtful consideration based on the researcher's clinical experience with the population studied. Additionally, the areas covered were an expansion of topics not covered by the standardized scales which will be discussed later in chapter #4. Finally, the intention of the questions was to capture the fathers' more detailed comments which potentially might be applied to service delivery improvement and clinical interventions.

The study focused on how Latino men define their masculinity and its relationship to the caregiving they provide to their children diagnosed with cancer. Additionally, it also evaluated the relationship between masculinity and how men cope with the challenges associated with having a child with cancer.

Masculinity

The independent variable was measured using the Gender Conflict Scale, also known as GRCS (O'Neil, Helms, Gable, David, & Wrightsman, 1986). The scale was developed to measure the reactions men experience to gender expectations. It targets the psychological impact of facing unrealistic and contradictory standards. It is a 37 item self-report measure designed to examine conflict with gender roles. Participants

responded to all items using a Likert scale of *strongly disagree* (1) to *strongly agree* (6). Higher scores on the GRCS indicate greater degree of conflict regarding the GRC factors. Subscale scores were calculated by adding up the subscale items and dividing by the number of items in that subscale. Some researchers have used an alternate mode to get the score by adding up all the items and dividing them by 37. There were four main factors in the scale:

- (1) *concerns with success, power and competition* (13 items) - refers to personal attitudes about success pursued through competition and power.
- (2) *restrictive emotionality* (10 items) - refers to restrictions and fears about expressing one's feelings as well as limitations in finding words to express basic emotions.
- (3) *restrictive affectionate behavior between men* (8 items) - this indicates restrictions in expressing one's feelings and thoughts with other men and difficulty touching other men.
- (4) *conflicts between work and leisure/family relations* (6 items) - this pertains to having restrictions in balancing work, school, and family relations which result in health problems, overwork, stress, and a lack of leisure and relaxation.

Research results indicate that the GRCS has good construct validity based on many factor analyses and tests of reliability and validity from varied samples (O'Neil, 2008). From the correlational data, the GRCS appears to have convergent validity with commonly used masculinity measures and discriminant validity with sex role egalitarianism and homophobia. The validity data indicate that the GRCS assesses a distinct construct from other masculinity measures and relates to measures of masculinity

ideology (Pleck, 1995), masculine norms (Mahalik et al., 2003), gender role stress (Eisler, 1995), and reference group identity (Wade & Gelso, 1998). Early work demonstrated that each of the subscales had acceptable reliabilities and validity across studies, with coefficient alphas ranging from .75 to .85 (Good et al., 1995; O'Neil, Good, & Holmes, 1995). In addition to its high validity as a factor in selecting it for this study, the GRCS was used because of its internal consistency tests with diverse groups. For example, the scale has been used with many populations including men from Europe, Canada and Asia as well as men who are gay, African American, Mexican Americans, Cuban Americans and Puerto Ricans (Torres Rivera, 1995; Carter, Williams, Juby, & Buckley, 2005; O'Neil, 2008). The scale was translated into Spanish and used with Puerto Rican men (Torres, 1998).

Caregiving

The Care of My Child with Cancer scale (Keegan Wells et al., 2002) was used to measure caregiving demands. This instrument consisted of 28 items with which family caregivers identify both the time spent in caregiving activities, and the effort associated with the various caregiving activities. Items are scored on a 5-point Likert-type scale with time broken down as none, <1 hour/week, 1-2 hours/week, 3-5 hours/week, and >5 hours/week. Effort also is scored on a 5-point Likert-type scale including none, a small amount, moderate, quite a lot and a great deal as the response choices. Overall scores are a sum of the individual calculated demand scores with a total range of 28 to 140. Higher scores estimate higher levels of demand associated with caregiving. Items for the instrument were developed by the authors through a two-step process including a review of literature and feedback from pediatric oncology nurses. The instrument was validated

by a sample of 158 primary family caregivers of children being treated at one of nine participating pediatric oncology institutions (12.4% of participants were Hispanic). Internal consistency was established through the calculation of Cronbach's alpha (0.93). Test-retest reliability was reported using Pearson's product-moment coefficient. A value of $r = 0.90$ was calculated following a retest interval of 3 to 7 days (Keegan Wells et al., 2002).

Coping

Coping was measured by the inclusion of the *Ways of Coping* revised scale (Folkman & Lazarus, 1985). The Ways of Coping (WOC) is a 66-item questionnaire (8 coping scales) containing a wide range of thoughts and acts that people use to deal with the internal and/or external demands of specific stressful encounters. Usually the encounter is described by the subject in an interview or in a brief written description saying who was involved, where it took place and what happened. Sometimes an encounter, such as a medical treatment or an academic examination, is selected by the investigator as the focus of the questionnaire. Participants respond on a 4-point Likert scale (0 = does not apply and/or not used; 1 = used somewhat; 2 = used quite a bit; 3 = used a great deal). Subscales are scored by the sum ratings for each.

The Ways of Coping items were analyzed using alpha and principal factoring with oblique rotation. The coping scales derived from the factor analytic procedures described their alphas as following: confrontive coping (alpha = .70); distancing (alpha = .61); self-controlling (alpha = .70); seeking social support (alpha = .76); accepting responsibility (alpha = .66); escape-avoidance (alpha = .72); problem-solving (alpha = .68); and positive reappraisal (alpha = .79). Sample size consisted of 75 married couples (Folkman,

Dunkel-Schetter, DeLongis, & Gruen, 1986). One major limitation of this and other coping scales is that they have been designed for a different culture (e.g., White, English speaking, middle class) and may have questionable validity for Latinos (Marin & Van Oss-Marin, 1989).

To evaluate the psychometric properties of coping measures and their use with Latino populations, Munet-Vilaró, Gregorich, & Folkman (2002) worked on a Spanish language version of the WOC questionnaire. The Spanish language translated scale was evaluated with Latino men in a large convenience sample. Data was collected from three Latino populations: island Puerto Ricans (n= 384), Mexicans from Mexico City (n=321), and Latinos living in the San Francisco Bay area (n=358). Their research findings suggest that the Spanish WOC has acceptable levels of reliability and is appropriate for research within diverse Latino populations. This translation was used in this current study for that reason and was administered to fathers who were Spanish-speaking only. Fathers who are English speaking-only will answer the English WOC.

Data Collection Procedures

The study consisted of a total of 20 men who were fathers of children with cancer. This was a convenience sample based on participants meeting inclusion criteria. The research was approved by two Institutional Review Boards (IRB): one at the Ann & Robert H. Lurie Children's Hospital of Chicago board and one at Loyola University Chicago. Lurie Children's Hospital IRB approved a partial waiver of the Health Insurance Portability and Accountability Act (HIPAA) to fulfill the need for accessing the protected health information (PHI) of children and their parents. This waiver was needed because a treating medical clinician would not be available to assist in recruiting of the

targeted population. In addition, the waiver was needed because there was no advertisement or any other institutional programs or activities that would provide the opportunity for screening/recruitment of participants. The information was accessed through the electronic medical chart (EpicCare). The PHI accessed was the following:

1. Name
2. Address (including any part of street, city, state, county, and zip codes)
3. Elements of dates (which includes date of birth, admission, discharge, etc.)
4. Medical record number

Potential participants were recruited from lists compiled daily by the Hematology/Oncology appointment scheduling system (this was available in Epic for outpatient clinics) and the daily census of patients hospitalized under the Hematology/Oncology service (this information was also available via Epic). The researcher reviewed potential participants' names with a board-certified oncologist, an advance practice nurse (APN) or the family's social worker to ensure that the patients were stable and families had no concerning psychosocial or medical issues which precluded them from participating in research and as specified in the exclusion criteria. The researcher invited potential participants via a face-to-face introduction of the study and provided a presentation letter that explained the purpose of the study.

The researcher conducted the Consent process which consisted of providing time for the fathers to read the form and ask any questions they had about the study and consenting to it. Fathers also received a copy of the Consent Form to keep. Scheduling of the interview was coordinated so that participants and the researcher could agree on a time and date. Only adult fathers provided their consent to participate in the study.

Consent Forms were available in both English and Spanish. Participants chose their language of preference. The participant's signature provided documentation of agreement to participate in the study.

To minimize the possibility of coercion or undue influence, the researcher explained to potential participants that the study was voluntary. The Consent Form included a statement that explained participants were free to choose to participate or decline participation. Participants were also free not to answer any question or to withdraw from participation at any time without penalty. The researcher explained that the decision to participate or not will have no effect on the services that the participant and his child are currently receiving or may receive in the future at the hospital.

Privacy and confidentiality were very important topics explained by the researcher to all potential participants. Fathers in the sample were recruited from a minority group. Those who are immigrants who have left their native countries and enter the United States without proper documentation need to feel safe during the interview process. This required extra caution and consideration when introducing the research and its purpose. No questions were asked pertaining to legal status or any related matter about citizenship. The researchers discussed with all fathers who participated how personal information was obtained, and how it was going to be used. Furthermore, the researcher discussed the safeguards put in place to protect the information collected and provisions to prevent inappropriate disclosures of Protected Health Information (PHI). This information (PHI) is defined by HIPPA safeguards as all personally identifiable health information that is held and transmitted by healthcare providers.

Consent and interviews with all fathers who agreed to participate were conducted in a private room in the outpatient area or in a designated private space on the inpatient floor. Consent Forms and questionnaires were maintained in a locked cabinet. There were no identifiers on the questionnaires except a code number assigned at the time which was separate from the participant's list. If a parent declined participation in the study his name was kept for tracking purposes only. His information was deleted after recruitment ended.

There was a face-to-face or phone interview, whichever was more convenient to participants. The interviewer asked each father their preferred language to conduct the interview. Sixteen fathers preferred the interviewed in Spanish and four indicated they preferred to do it in English. Language interpreting services were not needed because the interviewer spoke English and Spanish. The interviewer used a questionnaire and read the questions to the individual participant. Interview length of time took between 45 minutes to 1 hour. Phone interviews were conducted when a participant was unable to have a face-to-face interview due to difficult work schedule or other limitations to get to the hospital. In those cases, the researcher introduced the study to participants in their preferred language at the hospital and agreed on a time to place the call.

CHAPTER FOUR

RESEARCH FINDINGS

This chapter reports on the findings of the study from the interviews with the sample of Latino fathers who have a child with a cancer diagnosis. The first section utilizes descriptive statistics to describe the sample and the major scales used in the study. The next section uses bivariate analysis to test the relationship between the independent variable, masculinity, and the dependent variables, coping and caregiving. Finally, the last section provides a report on the findings of qualitative data obtained from the open-ended items from the interviews.

Descriptive Statistics

Data collected from questionnaires was entered and analyzed using the Statistical Package for the Social Sciences (SPSS, version 23.0).

This chapter is based on a sample of 20 Latino fathers of children with a diagnosis of cancer. The first section includes the main characteristics of the fathers in the sample and major independent and dependent variables.

Sociodemographic Information

As Table 1 shows, most of the fathers or 70% were Mexican. Two fathers were from Ecuador, one was from Honduras and one from Peru. The sample also included one father from Puerto Rico and one Mexican-American. Eleven fathers were married at the time of the interview while eight were unmarried. Only one was divorced. Fourteen

fathers were currently living with the child's mother. These included those married or cohabitating. Participants' age ranged between 26 and 55 years of age ($M = 39$, $SD = 8.02$).

Table 1. Nationality of Latino Fathers

	Frequency	Percent
Mexican	14	70.0
Ecuadorean	2	10.0
Honduran	1	5.0
Mexican-American	1	5.0
Peruvian	1	5.0
Puerto Rican	1	5.0
Total	20	100.0

Most of the participants described themselves as Christian. From this group, Roman Catholicism was the affiliation mentioned most frequently. Four parents indicated they had no religious affiliation.

Table 2. Religious Affiliation of Latino Fathers

	Frequency	Percent
Roman Catholic	13	65.0
Protestant	2	10.0
Church of Christ of Latter Day Saints (Mormons)	1	5.0
No religious affiliation	4	20.0
Total	20	100.0

Regarding education, two participants had school level of 4th grade or less. Five participants had some years of college studies but did not complete the degree. The highest education level achieved was a master's degree. Please refer to Table 3 for more details.

Table 3. School Level Achieved of Latino Fathers

Grade Level	Frequency	Percent
1st-4th grade	2	10.0
5-8th grade	5	25.0
9th-12 grade	6	30.0
Completed GED	1	5.0
Few years of college	5	25.0
Master's Degree	1	5.0
Total	20	100.0

Ninety-five percent of the fathers were employed. Only one father was unemployed because of a physical disability. This participant was receiving Social Security benefits as his source of income. Three of the fathers worked as forklift drivers, two worked as assistant managers, two had employment in a factory and two were cooks. In contrast, fathers reported that nine of their significant others, wives or cohabitating partners, were unemployed.

Table 4. Type of Employment of Latino Fathers

Employment Type	Frequency	Percent
Factory worker	3	15.0
Forklift driver	3	15.0
Assistant manager	2	10.0
Cook	2	10.0
Construction worker	1	5.0
Delivery	1	5.0
Dishwasher	1	5.0
Engineer	1	5.0
Hotel services	1	5.0
Housekeeper	1	5.0
Maintenance worker	1	5.0
Security official	1	5.0
Store clerk	1	5.0
Unemployed	1	5.0
Total	20	100.0

Most fathers in the sample resided in Chicago or its metropolitan area. However, four of them had to travel more than 40 miles to get to the hospital to be with the child during hospitalization or medical appointments.

Table 5. Latino Fathers' Location of Residence

Location	Frequency	Percent
Chicago	10	50.0
Near Chicago Suburbs	6	30.0
Far from Chicago suburban/metropolitan area	4	20.0
Total	20	100.0

Data about the children diagnosed with cancer was collected from information that fathers provided during interviews. Fourteen children were boys and six were girls. Half of the children were between the ages of one and nine years old. The youngest child was one-year-old and the oldest was 18-years-old at the time of the interview ($M = 2.50$, $SD = 1.82$). Most of the children were diagnosed with cancer in the previous 12 months. Four children were diagnosed more than 3 years ago.

Table 6. Time Since the Child's Cancer Diagnosis

	Frequency	Percent
3-5 months	5	25.0
6-8 months	5	25.0
9-12 months	4	20.0
More than 1 year but less than 2 years	2	10.0
More than 3 years	4	20.0
Total	20	100.0

Most of the children (12 cases) were diagnosed with leukemia. In terms of the others, two children had bone cancer (osteosarcoma), and six had some form of neoplasm, commonly known as a tumor (two children had it located in the eye, an

additional two children had it in the nerve cells, one child had it in the brain, and one child had it located in the abdominal area).

The number of children in the family, including the child with the cancer diagnosis, ranged from a minimum of one to a maximum of four children ($M = 2.40$, $SD = .94$). In four instances, the child with cancer was the only child in the family. Only one father reported to have a second child with a rare health condition requiring specialized medical care.

Masculinity

This section includes the results from the independent variable masculinity as measured by Likert-type items from the Gender Role Conflict Scale and its four subscales (O’Neil, Helms, Gable, David, & Wrightsman, 1986). The range of scores reported for the Gender Role Conflict Scale had a minimum of 71 and a maximum of 166. The mean was 109.40 ($SD = 24.15$). Table 7 shows results of the subscales used: (a) Conflicts Between Work and Leisure – Family Relations, (b) Success, Power, Competition, (c) Restrictive Emotionality, and (d) Restrictive Affectionate Behavior Between Men. Success, Power and Competition had the highest mean score (42.35), whereas Conflicts Between Work and Leisure – Family Relations had the lowest mean (18.15).

Table 7. Gender Role Conflict Subscale Global Scores

Subscale	N	Minimum	Maximum	Mean	SD
Success/Power/Competition	20	26 (1)	62 (78)	42.35	9.40
Restrictive Emotionality	20	10 (1)	47 (60)	27.65	10.01

Subscale	N	Minimum	Maximum	Mean	SD
Restrictive affectionate behavior between men	20	8 (1)	34 (48)	21.25	7.85
Conflicts between work and leisure family relations	20	6 (1)	36 (36)	18.15	8.41

In terms of interpreting the results, higher scores for Success, Power and Competition indicate more inclination to have attitudes about success pursued through competition and power. Higher scores for Conflicts Between Work and Leisure - Family Relations indicate challenges to balancing these areas. Thus, it results in overwork, stress, and a lack of leisure and relaxation. In regards to Restrictive Emotionality, these scores indicate that the higher they are the more often participants will endorse having restrictions and fears about expressing their feelings. Higher scores also indicate limitations in finding words to express basic emotions. Finally, scores for Restrictive Affectionate Behavior Between men indicate the level of participants' endorsement of restrictions in expressing their feelings and thoughts with other men and difficulty touching other members of the same sex. In general, scores indicate the participants' level of conflict with male gender expectations (O'Neil, Helms, Gable, David, & Wrightsman, 1986). Table 8 shows the specific frequencies for each masculinity item included in the questionnaire and the corresponding subscales (n = 20).

Table 8. Latino Fathers' Level of Agreement with Masculinity Statements

Level of Agreement	6 Strongly Agree	5	4	3	2	1 Strongly Disagree
Success, Power & Competition						
Moving up the career ladder is important to me.	9	2	2	1	3	3

Level of Agreement	6 Strongly Agree	5	4	3	2	1 Strongly Disagree
Making money is part of my idea of being a successful man.	5	0	5	5	2	3
I sometimes define my personal value by my career success.	2	4	2	3	4	5
I evaluate other people's value by their level of achievement and success.	3	6	1	2	3	5
I worry about failing and how it affects my doing well as a man.	4	0	0	6	1	9
Doing well all the time is important to me.	12	2	3	2	0	1
I often feel that I need to be in charge of those around me.	6	1	5	2	3	3
Competing with others is the best way to succeed.	3	1	2	4	1	9
Winning is a measure of my value and personal worth.	2	3	4	2	3	6
I strive to be more successful than others.	4	7	4	0	1	4
I am often concerned about how others evaluate my performance at work or school.	0	2	3	2	2	11
Being smarter or physically stronger than other men is important to me.	1	2	5	4	0	8
I like to feel superior to other people.	0	1	2	2	1	14

Level of Agreement	6 Strongly Agree	5	4	3	2	1 Strongly Disagree
Restricted Emotionality						
I have difficulty telling others I care about them.	3	4	3	2	2	6
Strong emotions are difficult for me to understand	1	4	2	4	4	5
Expressing feelings makes me feel open to attack by other people.	1	0	4	1	4	10
Talking about my feelings during sexual relations is difficult for me.	1	2	3	2	4	8
I have difficulty expressing my emotional needs to my partner.	0	2	4	2	3	9
I have difficulty expressing my tender feelings.	1	3	3	3	1	9
Telling others of my strong feelings is not part of my sexual behavior.	4	2	0	4	1	9
I often have trouble finding words that describe how I am feeling.	5	1	2	1	3	8
I do not like to show my emotions to other people.	3	5	2	3	2	5
Telling my partner my feelings about him/her during sex is difficult for me.	1	2	3	3	1	10

Level of Agreement	6 Strongly Agree	5	4	3	2	1 Strongly Disagree
Restrictive Affectionate Behavior Between Men						
Verbally expressing my love to another man is difficult for me.	6	5	1	0	3	5
Affection with other men makes me tense.	2	6	1	3	3	5
Expressing my emotions to other men is risky.	2	2	4	2	0	10
Men who touch other men make me uncomfortable.	4	2	2	2	1	9
Hugging other men is difficult for me.	3	2	1	3	3	8
I am sometimes hesitant to show my affection to men because of how others might perceive me.	3	1	2	3	3	8
Being very personal with other men makes me feel uncomfortable.	0	0	1	1	6	12
Men who are overly friendly to me make me wonder about their sexual preference.	1	0	0	2	1	16
Conflict Between Work and Leisure- Family Relations						
I feel torn between my hectic work schedule and caring for my health.	4	2	5	1	4	4

Level of Agreement	6 Strongly Agree	5	4	3	2	1 Strongly Disagree
My career, job, or school affects the quality of my leisure or family life.	4	0	5	0	2	9
Finding time to relax is difficult for me.	4	3	2	4	0	7
My needs to work or study keep me from my family or leisure more than I would like.	3	4	3	1	2	7
My work or school often disrupts other parts of my life (home, family, health, leisure).	3	3	3	1	1	9
Overwork and stress caused by a need to achieve on the job or in school, affects/hurts my life.	3	0	2	2	3	10

Caregiver's Coping

Caregiver's coping results are based on the Likert-type scale from the Ways of Coping revised scale (Folkman & Lazarus, 1985). It is important to note that the measure is not designed to assess coping styles or traits. The scale was designed as a process measure for a wide range of thoughts and actions that persons use to deal with the internal and/or external demands of specific stressful encounters. In this study with fathers these encounters are related to having a child diagnosed with cancer and the stress it may generate. Higher scores indicate that fathers are using more strategies (actions or thoughts) to deal with the internal and or external demands of the child's illness.

Participants were asked about their level of agreement to specific items and selected

among the 4-point Likert scale (0 = not used, 1 = used somewhat, 2 = used quite a bit, 3 = used a great deal). Total scores ranged from a minimum of 30.0 to a maximum of 92.0 ($M = 59.15$, $SD = 17.38$). Table 9 specifies the strategies that the participants reported.

The most frequent strategies that the fathers indicated they used quite a bit or a great deal of the time are identified with an asterisk.

Table 9. Frequency of Coping Strategies Used by Latino Fathers

Strategy	Not Used	Used Somewhat	Used Quite a Bit	Used a Great Deal
Just concentrated on what I had to do next—the next step. *	0	3	8	9
I tried to analyze the problem in order to understand it better. *	1	1	5	13
Turned to work or substitute activity to take my mind off things.	6	2	3	9
I felt that time would make a difference—the only thing to do was to wait.	3	4	7	6
Bargained or compromised to get something positive from the situation. *	2	3	4	11
I did something which I didn't think would work, but at least I was doing something.	6	5	5	4
Tried to get the person responsible to change his or her mind.	15	3	2	0
Talked to someone to find out more about the situation. *	1	3	3	13
Criticized or lectured myself.	6	4	6	4
Tried not to burn my bridges, but leave things open somewhat.	2	4	7	7

Strategy	Not Used	Used Somewhat	Used Quite a Bit	Used a Great Deal
Hoped a miracle would happen. *	1	2	3	14
Went along with fate; sometimes I just have bad luck.	7	4	4	5
Went on as if nothing had happened.	13	3	1	3
I tried to keep my feelings to myself.	4	4	7	5
Looked for the silver lining, so to speak; tried to look on the bright side of things. *	1	0	4	15
Slept more than usual.	14	3	2	1
I expressed anger to the person(s) who caused the problem.	15	2	2	1
Accepted sympathy and understanding from someone. *	2	2	5	11
I told myself things that helped me to feel better.*	2	3	7	8
I was inspired to do something creative.	4	2	8	6
Tried to forget the whole thing.	12	3	3	2
I got professional help.	14	2	1	3
Changed or grew as a person in a good way. *	1	1	7	11
I waited to see what would happen before doing anything.	6	4	8	2
I apologized or did something to make up.	8	0	12	0
I made a plan of action and followed it.	5	3	5	7
I accepted the next best thing to what I wanted.	6	3	8	3
I let my feelings out somehow.	3	4	7	6
Realized I brought the problem on myself.	17	2	1	0

Strategy	Not Used	Used Somewhat	Used Quite a Bit	Used a Great Deal
I came out of the experience better than when I went in.	7	2	4	7
Talked to someone who could do something concrete about the problem.	6	2	6	6
Got away from it for a while; tried to rest or take a vacation.	12	6	1	1
Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.	15	1	3	1
Took a big chance or did something very risky.	19	1	0	0
I tried not to act too hastily or follow my first hunch.	8	5	3	4
Found new faith.	5	2	6	7
Maintained my pride and kept a stiff upper lip.	5	4	7	4
Rediscovered what is important in life. *	1	2	3	14
Changed something so things would turn out all right. *	4	1	10	5
Avoided being with people in general.	9	4	2	5
Didn't let it get to me; refused to think too much about it.	8	4	6	2
I asked a relative or friend I respected for advice.	4	4	4	8
Kept others from knowing how bad things were.	8	3	5	4
Made light of the situation; refused to get too serious about it.	13	0	6	1
Talked to someone about how I was feeling.	3	4	8	5

Strategy	Not Used	Used Somewhat	Used Quite a Bit	Used a Great Deal
Stood my ground and fought for what I wanted. *	1	2	8	9
Took it out on other people.	15	1	2	2
Drew on my past experiences; I was in a similar situation before.	16	0	0	4
I knew what had to be done, so I doubled my efforts to make things work.	3	3	4	10
Refused to believe that it had happened.	9	4	3	4
I made a promise to myself that things would be different next time.	6	3	4	7
Came up with a couple of different solutions to the problem.	8	4	8	0
Accepted it, since nothing could be done.	3	4	6	7
I tried to keep my feelings from interfering with other things too much.	3	3	10	4
Wished that I could change what had happened or how I felt.*	3	2	5	10
I changed something about myself.	5	2	5	8
I daydreamed or imagined a better time or place than the one I was in.	8	2	5	5
Wished that the situation would go away or somehow be over with.	4	2	4	10
Had fantasies or wishes about how things might turn out.	5	3	2	10
I prayed. *	1	2	1	16

Question	Not Used	Used Somewhat	Used Quite a Bit	Used a Great Deal
I prepared myself for the worst.	7	0	6	7
I went over in my mind what I would say or do.	4	2	5	9
I thought about how a person I admire would handle this situation and used that as a model.	9	3	3	5
I tried to see things from the other person's point of view.	5	5	5	5
I reminded myself how much worse things could be. *	1	2	5	12
I jogged or exercised.	9	3	5	3

As Table 9 indicates, fathers endorsed a variety of actions or thoughts related to coping which included: prayer, rediscovering what's important in life, analyzing the problem to understand it better, and wished they could change what happened.

In addition to the data presented in Table 9, many participants in the sample reported specific coping strategies that they never used: (a) 14 fathers said they never got professional help, (b) 15 fathers said they never tried to feel better by eating, drinking, smoking, using drugs or medication, and (c) 19 fathers said they never took a big chance or did something very risky.

Besides the coping strategies, participants indicated multiple emotions when they got the news about the child's diagnosis. Fathers were given a list of emotions to choose from to describe their feelings. Thirteen fathers indicated they felt sad, and ten fathers felt confused. A small number of participants indicated feelings of emptiness and disappointment when they received the news about the child's diagnosis. Comparing when they first learned of their child's diagnosis with how they felt after, 11 fathers were

hopeful and ten fathers indicated they felt optimistic; however, eight fathers still felt sad.

The top three ranking emotions at the time of diagnosis, confused, sad and afraid, decreased by the time of the interview. Table 10 provides a detailed list of the emotions reported by the participants (n = 20). The minimum time lapsed after diagnosis was 3 months and the maximum was close to 3 years.

Table 10. Frequency of Pre and Post Emotions in Relation to the Child's Diagnosis

Emotions at Time of Diagnosis	Frequency	Emotions Post Diagnosis	Frequency
Sad	13	Hopeful	11
Confused	10	Optimistic	10
Afraid	10	Sad	8
Skeptical	9	Happy	2
Angry	6	Afraid	5
Guilty	4	Hopeless	2
Hopeless	4	Angry	1
Surprised	2	Confused	1
Powerless	2	Guilty	1
Disappointment	2		
Emptiness	2		

Finally, participants talked about their immediate supports. Specifically, they were asked to indicate the three most important persons they can count on to get help in relation to having a child diagnosed with cancer as indicated in Table 11 below. Most participants could name only two significant supports. Seventeen fathers or 85% indicated they relied on relatives and twelve, that is 60%, mentioned their spouses as the person they can count on. On the other hand, only three of them mentioned their co-workers as a source of support. Two participants stated they relied on friends and one indicated the hospital social worker was an important person to get help from.

Table 11. Fathers' Sources of Support

Source	Frequency
Relatives	17
Spouse	12

Source	Frequency
Co-workers	3
Friends	2
Physician	2
Teacher	2
Hospital social worker	1
Pastor, priest or spiritual leader	0
Counselor or therapist	0

Caregiving

This section highlights the most notable results of caregiving based on the global sample response from fathers' completion of The Care of My Child with Cancer Scale (Keegan Wells et al., 2002). Data is based on a Likert-type scale that captured the amount of effort and activity level provided to the children by their fathers.

The activities were measured by the number of hours per week dedicated to each activity. The scale's global score for the fathers ranged from a minimum of 30.00 to a maximum of 92.00. The mean was 59.15 ($SD = 17.38$). The caregiving activities were categorized into five domains: (a) communication, (b) emotional care, (c) family and interpersonal relationships, (d) finances and (d) physical care. Fathers' responses ($n = 20$) to individual items were added to obtain scores in each domain. Global scores for the domains are presented in Table 12. It shows that physical care and emotional care resulted with the highest means among the five domains. However, it is important to note that domain scores are not equivalent due to the differences in the number of items in each. For example, the low score for finances was due to the domain having only one item while physical care included thirteen items. Thus, each domain must be considered on its own. A minimum score of zero indicates that there were fathers who did not perform the activity.

Table 12. Total Caregiving Scores for Each Domain

Type of Care	F	Minimum	Maximum	Mean	SD
Communication	20	2.00	12.00	7.85	3.20
Emotional Care	20	11.00	27.00	19.55	3.90
Family/Interpersonal	20	0	14.00	7.55	4.84
Finances	20	0	4.00	2.80	1.51
Physical Care	20	5.00	44.00	21.40	9.73

There were five caregiving activities that fathers endorsed most frequently: (a) time spent during appointments at the hospital, (b) provide emotional support to the child, (c) travel to and from the hospital, (d) comfort the child through the pain of the cancer and its treatment and (e) taking care of discipline and/or behavior problems. On the other hand, four of the least endorsed caregiving activities were related to administering medication and its equipment: (a) preparing and giving medicines, fluids and TPN (nutrition) intravenously (IV), (b) preparing and giving medicine as a shot in the muscle (IM) or under the skin, (c) preparing and giving catheter flushes, and (d) changing the dressing on the child's catheter. Most of the fathers indicated they did not perform these activities because someone else was doing them such as the nurse or the patient's mother or because it was not part of the treatment when the interview was done. Table 13 provides a list of the caregiving activities and the number of fathers who endorsed them.

Table 13. List of Caregiving Activities Reported by Latino Fathers

Type of Care	Amount of Effort in Hours During a One-Week Period				
	0	< 1	1-2	>2 - <5	> 5
Physical Care					
Preparing and giving medicines, fluids and TPN (nutrition) intravenously.	15	1	2	0	2

Type of Care	Amount of Effort in Hours During a One-Week Period				
	0	< 1	1-2	>2 - <5	> 5
Preparing and giving medicine as a shot in the muscle or under the skin.	18	0	2	0	0
Preparing and giving medications by mouth.	4	8	3	3	2
Preparing and giving catheter flushes.	16	1	1	0	2
Changing the dressing on your child's catheter.	16	3	1	0	0
Managing side effects of cancer or its treatment.	8	3	2	5	2
Keeping your child comfortable and without pain.	3	3	2	5	7
Managing other childhood illnesses for your child with cancer.	5	2	4	3	6
Managing unexpected events related to your child's illness.	6	3	0	6	5
Additional household tasks related to your child's illness.	5	2	3	5	5
Coordinating, arranging, and managing medical services.	8	4	2	3	3
Travel to and from the hospital for medical care.	2	0	1	7	10
Time spent at the hospital for appointments.	2	0	0	7	11
Emotional Care					
Providing emotional support for your child with cancer.	0	0	1	6	13
Providing emotional support for other children in the family.	3	2	0	5	10
Providing emotional support for the extended family.	6	1	9	2	2

Type of Care	Amount of Effort in Hours During a One-Week Period				
	0	< 1	1-2	>2 - <5	> 5
Providing emotional support for your spouse/partner.	3	1	1	4	11
Meeting your own emotional support needs.	4	2	4	3	7
Comforting your child through the pain of the cancer and its treatment.	1	1	1	5	12
Taking care of discipline and/or behavior problems of the child with cancer.	4	0	0	7	9
Finances					
Taking care of finances, bills, and forms related to the child's illness.	3	1	3	3	10
Family / Interpersonal Relationships					
Planning activities for your child with cancer around the treatment and illness.	4	1	1	7	7
Planning activities with your family around the treatment and illness.	5	0	8	6	1
Getting child care / babysitting help for your ill child.	8	1	6	2	3
Obtaining child care/ babysitting for brothers and sisters of the ill child.	9	1	3	5	2
Communication					
Communicating information about cancer to schools, day care, babysitters, extended family and friends.	2	3	1	5	9

Type of Care	Amount of Effort in Hours During a One-Week Period				
	0	< 1	1-2	>2 - <5	> 5
Watching and reporting your child's physical symptoms and medical condition to the medical team.	3	3	3	2	9
Getting information on your child's illness and treatment.	2	2	2	12	2

Bivariate Analysis

Next, the researcher conducted statistical tests to address the main research questions. Bivariate correlation tests were used to determine the degree of relationship between the two quantitative variables under study. All the main variables in this study (masculinity, caregiving and coping) are continuous, so they meet criteria for correlational tests. There are two research questions that the bivariate tests were addressing:

- 1. What is the relationship between Latino fathers' masculinity and their caregiving activities?**
- 2. What is the relationship between Latino fathers' masculinity and the ways in which they cope with pediatric illness?**

Thus, the study considered the degree of relationship between Latino fathers' masculinity and their caregiving activities by measuring the fathers' scores to the Gender Role Conflict Scale (O'Neil, Helms, Gable, David, & Wrightsman, 1986) with the scores from their answers to The Care of My Child with Cancer Scale (Keegan Wells et al., 2002).

An additional test was done to evaluate the relationship between masculinity and fathers' coping. Thus, the Gender Role Conflict Scale (O'Neil, Helms, Gable, David, & Wrightsman, 1986) was correlated with the Ways of Coping revised scale (Folkman & Lazarus, 1985).

Results from the statistical tests of global scores indicated no significant relationship between masculinity and caregiving. Likewise, masculinity and coping did not show a significant relationship. Additional correlation tests were done to determine if there was any relationship between the masculinity subcategories of Restricted Emotionality (RE), Conflicts Between Work and Leisure - Family Relations (CWL), Success, Power, Competition (SPC) and Restrictive Affectionate Behavior Between Men (RABBM) and the Coping and Caregiving variables.

As table 13 indicates, there was a significant relationship between Conflict Between Work and Leisure - Family Relations and Coping. There was also a relationship between Restrictive Emotionality and Conflict Between Work and Leisure - Family Relations. This means that fathers had an increasing level of disruption between their need to work, family life expectations and personal needs. Along with that, they used more coping strategies to deal with the stress they were experiencing. The more fathers experienced conflicts between work and family, the more they used strategies to cope with the demands of their roles. Finally, when fathers conflict between work and family life increased, they also showed an increase in their conflict about expressing their emotions.

Table 13. Correlation Matrix of Masculinity Subscales and Dependent Variables

Variable	N	CWL	RABBM	RE	SPC
Coping	20	.48 ($p = .03$)	-.17 ($p = .47$)	.15 ($p = .53$)	.11 ($p = .65$)
Caregiving	20	.14 ($p = .55$)	-.07 ($p = .77$)	.26 ($p = .28$)	-.35 ($p = .13$)
CWL	20	–	–	–	–
RABBM	20	.25 ($p = .28$)	–	–	–
RE	20	.55 ($p = .01$)	.51 ($p = .02$)	–	–
SPC	20	.07 ($p = .77$)	.12 ($p = .63$)	.15 ($p = .53$)	–

Note: Correlation is significant at the 0.05 level (2-tailed). CWL= Conflict Between Work and Leisure – Family Relations; RABBM = Restrictive Affectionate Behavior Between Men; RE= Restrictive Emotionality; SPC = Success, Power and Competition

This concludes the quantitative data results for the variables masculinity, caregiving and coping. The next section of this report includes qualitative data which was reported by the fathers in the study.

Qualitative Data

This section presents results from data obtained to address the third research question. This part describes participants' responses to three open-ended questions included in the questionnaire. Qualitative data emerged from the questionnaire's open-ended questions:

1. Aspects that fathers found most helpful. This was included in the question:

What did you find most helpful during your visits or stays in the hospital with your child?

2. Participants' description of responsibilities. This was included in the question:

What do you think are your most important responsibilities as a father?

3. Participants' advice to other fathers. This was included in the questions, *as a father, what would you like to tell other fathers who find out their child is seriously ill?* and *what advice would you like to give them?*

Fathers' responses were entered into a computer and converted to an Excel spreadsheet format for a general initial evaluation. These responses were then entered into the qualitative software NVivo and coded for special groupings, also known as nodes. The researcher asked one licensed clinical social worker (with a master's degree in social work) to review the coding and compare how the researcher organized the data. Both approaches were compared. Minor revisions were completed based on feedback received and an agreement was reached on the topics from the open-ended questions.

Sixteen interviews were conducted in Spanish and four in English based on participants' preferred language. The researcher was fluent in both English and Spanish languages. The answers in Spanish were transcribed verbatim into the questionnaires. The researcher then translated all the answers from Spanish to English for analysis in NVivo.

The initial coding was completed by reading the raw data. The NVivo software has functions that were utilized to identify repeating patterns such as phrases and single words which were consequently integrated into the content analysis. Also, known as nodes, these contain qualitative data which was tagged and subcategorized as repeating units within the data collected in the interviews and the fathers' comments. Concern for the child with cancer was the topic most frequently discussed in the fathers' comments. There were 28 references about the child. Physicians and hospital staff were very often mentioned as sources of support, information and being helpful in general. There were 22 references in which fathers spoke of the staff role, care and significance. Table 14

provides a detailed list of the nodes developed from the content of the fathers' answers to the qualitative questions.

Table 14. List of Nodes and Frequencies from Qualitative Questions

Node	Number of References
Child	28
Physicians and medical staff	22
Provider/providing care	20
Faith	12
God	16
Hope	9
Emotions	8
Illness of the child	7
Education	6
Prayer	6
Wife	6
Medical treatment	6
Fight to persist	5
Son	3
Love	4
Social worker	3
To have company/or provide company	2
Resources	2
Cancer	1

Node	Number of References
Crying	2
Kindness	1
Tenderness	1
Trust	1

The nodes were categorized into general groupings. The general categories developed from the process were: (a) Types of caregiving (b) Fathers' roles and responsibilities, and (c) Coping. Various subtopics emerged from additional review and segmentation of the interview responses that fathers provided. These were: (a) Healthcare providers as caregivers, (b) Fathers' caregiving and role, and (c) Projecting forward with optimism and faith.

Following are the three qualitative questions that fathers answered and examples to illustrate their responses. The questions reflect a more comprehensive explanation of how the nodes listed in the table above were used by the fathers to illustrate their role, caregiving and coping with their situation. Each father's statement is identified by the letter "R" and a number. Each combination of letter and number corresponds to a different father.

A. What did you find most helpful during your visits or stays in the hospital with your child?

Fifteen fathers mentioned the medical team had an important supportive role to instill a level of trust in the treatment process. Fathers indicated it was very useful to have access to the physicians, nurses and social workers. One father also mentioned the

supportive role of the peer to peer program volunteers known as ParentWise.

R19: The MDs, staff always looking for us; tenderness and kindness towards family and the patient. Social workers provide emotional support, seeking help with resources, including financial. We have cried with our social worker and received support as we cope with the illness.

R17: The hospital environment made me feel confident; the medical team and their level of care. I've never seen so many MDs and staff, [they] gave me a sense of trust. The conversations with the MDs and their comments about not worrying in relation to the future. I appreciate the moment. Good staff approach. Social workers brought resources and alternatives.

However, two fathers felt they had to show the world a different face from what they were truly feeling inside. One father spoke about controlling his emotions and demonstrating happiness.

R02: Sometimes, I don't feel well emotionally even though externally I'm making jokes and whistling.

R05: Control your emotions when close to other people. The happier you are, that feeds your child. It's no one's fault.

R08: Sometimes words are fake. It is not what they truly feel.

Fathers talked about their initial emotional reaction and the challenges they struggled with.

R11: It has been difficult to be in this.

R12: It may be frightening in the beginning, but you feel more calmed later. You realize that yourself and you can find comfort in the hospital.

R16: I could not hear or mention the word 'cancer'.

Three fathers mentioned the importance of talking about their experience and seeking help.

R16: We had to seek professional help.

R19: Talk. There are many things we need to talk. It's a way to vent.

R20: It is okay to talk to people. It's ok to express your emotions. You have to get it out and cry. Let it out, not keeping it in. No need for stress or anger to build up. It's ok to be disappointed with yourself.

B. What do you think are your most important responsibilities as a father?

Twelve fathers indicated that their most important responsibility was to be a provider to the child and the family. They mentioned they took care of tangible things such as meeting the family's basic needs, taking care of financial responsibilities, entertainment and homework. Fathers also talked about providing emotional care.

R01: To provide care to my child, my house, pay the bills, school, provide food. I am related to everything.

R02: To help my child as much as possible, emotional support, entertainment, going to the movies, go out to dinner, do shopping.

R05: To provide them and cultivate love, faith and hope.

R07: The most important thing is my family; to please my family as I am able (vacations, gifts).

R08: Caring and loving your child.

R09: For my children to have everything, both economically and morally.

R13: Make sure I'm a provider. Being financially stable, protector.

R15: The first, to provide what's needed at home. Dedicate time to my family, time for entertainment, health, help them with homework. Offer company and affection; demonstrate how much you love them.

One participant mentioned the importance of supporting his child's medical needs and being vigilant about physical health.

R12: My son's well-being. Never miss his appointments and be alert to his medications. You have to be alert about your children, because if you become distant, it may be too late. Pay attention to signals and be alert to illnesses.

Three fathers talked about the responsibility to make sure their children are raised adequately and have a role in society.

R03: My children's health and well-being, their development, most of all, and functioning in society because children learn from their parents.

R05: To provide them education so they can leave a legacy in this world.

It included one father who made a statement about specific goals according to the child's gender.

R17: Raise girls to be respectful, with values, to have a voice. Boys have to contribute to society.

Six fathers mentioned concern for their spouse and her well-being in the relationship. One divorced father mentioned being available to his ex-wife.

R11: My wife is first because she gave me my child. If you have a wife, communicate with her. Sometimes there is conflict and both parties have to work it out.

R07: Help your family and your wife. Put yourself on expert hands, physicians, and follow their instructions. There are cures. The wife is the one who hurts the most in the process.

Two of the fathers indicated they relegated the care of their personal needs.

R17: In my family I was raised to be the father for everyone. I put my education needs in the backburner to take care of kids and family.

R08: Sometimes my needs are left out and are not so important.

C. As a father, what would you like to tell other fathers who find out their child is seriously ill and what advice would you like to give them?

Participants used the word "God" in 16 instances. Faith was mentioned on 12 occasions. Most of the time the references to God were related to trusting the divine power, to be patient and pray. Faith was related to God and having hope. Fathers used the word "hope" in nine instances.

R02: I ask God for all this to end. Faith in God.

R03: Faith and connection with God.

R05: My faith in God. Never give up hope. Wait, because we can't change things. My best ally has been time.

R05: I can't comfort you, but you can wait in God. Time will give you many answers. Be patient, never get desperate.

R06: Have a lot of faith in God. Place your child in God's hands and he will determine what will happen. Don't worry. If I ask them [the fathers] to not be sad, that's impossible. There is hope.

R14: Communication is very important and providing hope.

R15: You have to fight for your children's life. Physicians know a lot, but God has the last word and miracles exist.

Two fathers used the phrase "*echele ganas*" which is a colloquial expression among Mexicans to denote a sense of going forward, to put the best effort into something.

R02: *Échele ganas*. It's with God's company that you can achieve it.

R04: *Échele ganas*. Care for them [the children who have cancer], it can happen to all of us. Faith is what you have. God.

Advice to other fathers included three comments about having a positive attitude, to persist and being optimistic.

R01: To keep the fight, do the best they can for their child. There's nothing more important.

R07: Be strong, think positively.

R10: Take it day by day. Don't rush things. Keep hoping for the best, keep fighting.

However, one father had a different perspective about feeling optimistic.

R08: It's hard to say 'be optimistic.' Your kid can be sick and it depends on how other kids are doing. They may be worse than yours. How can you tell them when you don't know what they are going through?

Finally, one father spoke about being thoughtful and avoiding regulated substances.

R09: Have a thorough analysis of things. Do not use alcohol or drugs.

As a summary, the three qualitative questions provided fathers with the opportunity to talk in more detail about their roles as caregivers. The questions also engaged the fathers to speak about what they considered supportive and helpful as they coped with the child's illness and his or her treatment. Fathers indicated that their most important responsibility was to be a provider to the child and the family. They mentioned they took care of very concrete matters and meeting basic needs. They also spoke about emotional care as part of their role and being available to support their significant others, specifically their spouses. Fathers indicated the importance of talking about their experience and seeking help while others, in contrast, spoke about showing externally a different face from what they were truly feeling inside and controlling their emotions. In addition, the medical team and its supportive role was mentioned several times as another important component of the care provided to the children. On the other hand, fathers' advice to other men coping with a similar situation included several references to God, faith and hope as key elements. Suggestions in this area, with a few exceptions, revolved around having a positive attitude, to persist and being optimistic.

CHAPTER FIVE

DISCUSSION

This chapter presents noteworthy aspects of the study results and remarks about relationships presented in the previous chapter as they pertain to the two main sections: the quantitative and the qualitative aspects of the research. Additionally, this chapter also includes the implications of the results for the profession of social work. Finally, the chapter provides recommendations for future research.

The study addressed the questions of (a) what is the relationship between Latino fathers' masculinity and their caregiving activities? (b) what is the relationship between Latino fathers' masculinity and the ways in which they cope with pediatric illness? The third and last question addressed how do Latino fathers define the tasks and responsibilities they have in their caregiving role. The first two questions were addressed with the quantitative data obtained. The third question is discussed from the qualitative statements of the fathers. The discussion will integrate both qualitative and quantitative frameworks to explain the data and obtain a broader perspective of the problem under consideration and the study results.

The results indicated no significant relationship between the independent variable masculinity and the two dependent variables of coping and caregiving when looking at their global scores. However, when subscales were analyzed, there was a positive correlation between one of the components of masculinity, that is, Conflict Between Work

and Leisure - Family Relations and Coping (WOC). These results should be used with caution due to the small sample size. Therefore, some initial impressions are pertinent in this exploration. One explanation for this relationship may be related to the high level of involvement fathers reported and the stress generated when they had to cope with the many demands of work, family life and having a child with cancer. All the fathers included in the sample were frequently in the hospital with their child. In many instances, these men were there by themselves while their spouses or significant others were taking care of other responsibilities outside the hospital. Many of the fathers reported informally that they would alternate days or hours with the mothers to make the burden easier on the two. Others had no employee benefits and consequently had to balance between taking time off from work to be present by the bedside with the child while also meeting their responsibilities as main income earners for the family.

Qualitative data complemented the previous assumption as fathers indicated their primary responsibility was being a provider. This means that the stability of the family would be jeopardized if the fathers stop earning income and providing for the basic needs of the family unit. This situation suggests a higher level of coping strategies from fathers as they were involved in providing care while at the same time meeting the demands of their employers and other duties. With many demands on their time, parents ask themselves whether they are spending the right amount of time providing care to their children. The study results confirm evidence from previous studies that indicate that many working fathers report feeling stressed and in conflict about juggling work and family life and find it very or somewhat difficult to balance these responsibilities (Brown & Barbarin, 1996; Chesler & Parry, 2001; McGrath & Huff, 2003; Parker & Wang, 2013). For the

Latino fathers in the sample, it meant dealing with the tension between having their child with cancer as their priority and the concerns about their jobs.

In this case, fathers' role departs from the traditional division of labor as they demonstrate a complex gendered practice. Fathers in the sample demonstrated a high level of involvement in the child's physical care and emotional care even as they fulfilled more traditional male gender role responsibilities such as procuring economic stability, entertainment, and assuming the role of protector. This outcome is supported by research from Coltrane, Parke, & Adams (2004) who indicated that in the case of Mexican American men, those who interacted with children in feminine-typed activities such as cooking, reading, shopping and playing indoor games also interacted with them in masculine-typed activities like hobbies, outdoor games, and spectator entertainment. Some fathers indicated that they placed their own needs aside to attend the child's needs. This may be related to the correlation between their restricted emotionality such as expressing their own emotional needs and the conflict they experienced with work and leisure to be with family. Thus, this research suggests that Latino fathers find themselves pulled to fulfill traditional masculinity role expectations as well as the situational needs of their families.

The study raises a word of caution against restricting masculinity into a single interpretation and how Latino fathers perform their role as caregivers. This masculinity adds to the complexity of the traditional notions that reproduce men's role as provider in the family. Although in the past male power depended on the capacity to economically sustain the family, the fathers in this study subvert traditional roles because of the reality of having a child with cancer and the need to be flexible and accommodating to what

works for the family. This accommodation may require performing a role that in some instances may be considered traditional male gendered behavior while also incorporating more female-identified duties. This heterodox masculinity (Rodriguez Cerda & Ambriz Bustos, 2005) is constructed by patterns of patriarchal elements coexisting with models of family life and care of equality in gender relations. As an example, fathers in the study were in charge of paying the bills and overseeing the family finances. However, their role also involved spending time at the hospital to provide care to their child. In some cases, they seemed to conform to gender norm expectations while in others they acted as if they were attempting to break from those expectations. Thus, this may lead to the emergence of conflict with social and cultural gender norm impositions and what is defined as being a man.

Therefore, in relation to expectations, gender role conflict theory (GRC) assumes that the rigid, restrictive, and sexist attitudes toward gender roles can cause negative consequences for men when they are not able to express their emotions about what it means to have a child with cancer, and feeling like they need to be in control and appear strong. On the other hand, it may be interpreted as liberating for these men when they find the space to articulate their fears, concerns and thoughts in a welcoming and empathetic environment such as the hospital, talking to a physician, or being in the company of their spouses, significant others or the extended family.

It seemed very challenging for the fathers in this sample to take care of their own needs while also meeting the needs of others in the family, including the child. It becomes a matter of priority which area becomes the focus of attention. Qualitative data indicated that the caring for the child's well-being was the main concern for participants. Many

indicated not seeking professional help for themselves. Others did not have the space to talk about their feelings, even though this was something they desired and deemed important to cope with the challenges of having a child with cancer. There is one point to highlight here. These men demonstrated the willingness and capacity to be open and in touch with multiple emotions during and after the diagnosis. They talked about the importance of providing emotional care to their children and family and brought painful experiences to the interview process. This is a departure from the traditional conceptions of the Latino male and the alleged pervasive machismo in that culture. Although limited, this data adds to the discussion about masculinity and how men express their emotionality. It also highlights the social transformation that may be occurring in relation to a shift in gender roles. Their roles and behaviors may signal to changes occurring on how men perform their masculinity and break away from traditional gender norms.

On the other hand, it is uncertain whether this sample of Latino fathers may be more inclined to integrate gender egalitarianism in their relationships as reported in multiple studies (Coltrane, Park & Adams, 2004; Doucet, 2004; Pelchat, Lefebvre & Levert, 2007, Falicov, 2010; Galinsky, Aumann & Bond, 2011). Although this study found evidence that Latino fathers dedicated several hours to the caregiving of the sick child, there was no evidence to support an egalitarian relationship with the other children or spouses because these aspects were not explored in the study.

However, qualitative data provided new information that was not expected initially when the study was designed. This pertains to themes that emerged after the data analysis. Hope, faith and spirituality emerged as very important to many fathers in the sample. Childhood cancer presented these fathers with opportunities to consider and

reflect on the meaning of many aspects in their lives. Some of the participants described themselves as not affiliated to religion, but a considerable additional number turned to spirituality and belief in a higher source of power to sustain their coping. Fathers in the sample were very open to share their beliefs and talk about their faith in very optimistic ways. Most of them indicated they used prayer as a coping strategy. These findings are supported by research that indicates that spirituality helps pediatric patients and their families to find meaning in the cancer experience. Parents confronted with the childhood cancer experience may re-evaluate their lives, careers and relationships (Jones, Pelletier, Decker, Barczyk, & Dungan, 2010). It provides them with an opportunity to re-visit their spirituality, confront existential beliefs and deal with the “why me” or “why my child” questions to make sense of their experience (Chesler & Parry, 2001; Neil-Urban & Jones, 2002; Yeh, 2004).

Another theme that emerged in the comments from the fathers in the study was the role of the hospital team and the quality of care. Their opinion of the attention that physicians and the healthcare staff provided was very positive. Fathers in the sample indicated the importance of conversations with the physicians and the value of having a team of service providers who were readily available. This finding is supported by earlier research which indicates that fathers report the value of developing partnerships with their healthcare professionals, meeting face-to-face with them to obtain straightforward information about their child’s condition, and learn to communicate this information with their children (Brody & Simmons, 2007; Kratz, Uding, Trahms, Villareale & Kieckhefer, 2009; Ljungman et al., 2003).

Implications for Social Work

Social work and 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. This study calls for the involvement of social workers to collaborate with parents, especially those from ethnic minorities and advocate for adequate services to this population. It is important for social workers to promote new spaces of interaction in which Latino men feel welcomed to share their concerns and feelings about the challenges they face when they have a child with cancer. These spaces include the flexibility and creativity to foster connections with hospital and community providers who can also serve this population and facilitate support in multiple areas such as financial resources, psychotherapeutic services, mentoring, parenting classes, case managers, spiritual and religious leaders and court advocates, among others.

Fathers may benefit from structured support activities that allow them to express their concerns in a safe and validated setting. Many fathers continue to believe that their primary role during the cancer experience is to remain strong and suppress their emotions for the benefit of other family members (Brody & Simmons, 2007; Chesler & Parry, 2001; Neil-Urban & Jones, 2002). Social workers can help facilitate opportunities for fathers to express their anxiety, doubts, sense of alienation, and vulnerability through community based groups, Web-based care pages, and parent to-parent support matching such as ParentWise, which some fathers found useful while in the hospital.

Based on what the Latino fathers indicated as helpful, efforts are suggested to continue 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 can have their voices and cultural stories heard (Torres, Solberg, & Carlstrom, 2002). Although most of the fathers did not seek professional help, this does not preclude practitioners from promoting access to psychotherapeutic care, especially for those men with limited financial means who may not be able to afford traditional psychotherapy. Including the extended family and spouse/significant other is also another avenue to explore as many of the fathers in the study indicated the importance of these persons in their caregiving experience. It is in tune with values of familismo within the Latino community.

It is also pertinent to validate fathers' resourcefulness. Men in the study relied on a diverse array of coping strategies to manage stress. Social workers can approach an understanding of coping that is non-judgmental by avoiding conceptions of coping into "good" versus "bad" or "appropriate" versus "inadequate" categories. Language plays an important function on how coping is socially constructed and social workers can make a difference to eliminate stigmatization. The fathers in this study coped in a variety of ways depending on each situation. Therefore, a person-in-the environment approach is a pertinent framework to assess their situation and life experience. Additionally, social work as a profession is in a special position to promote a communitarian approach to caregiving in which the responsibility for the care is shared among multiple persons and eases the burden on the parent.

In relation to social work education, schools need to emphasize on the study of the rapid changes that the United States' healthcare system is undergoing and how it may affect the role of social workers in those settings when providing services to minorities. Schools need to teach about the opportunities available in healthcare and motivate

students to explore this as a field of intervention in which clinical work is needed. Social work students need to be equipped with adequate theoretical frameworks to assess and intervene with patients and their families affected by life-threatening illness.

Schools need to prepare social workers with adequate cultural competencies to engage with minority populations and develop the skills to navigate public systems such as government entities, care coordination entities and non-for-profit organizations that serve the population of this study. 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).

In addition, at a policy level, it is imperative for social workers to be trained in advocacy to promote more worker's rights and employee benefits including parental leave for men who are caregivers. Men in the study struggled with meeting the demands of work and caring for a child with cancer. Social workers have an important role in raising the level of consciousness about the extraordinary demands of caring for a child with cancer and other life-threatening illnesses and how a father's financial, physical, and emotional strategies to cope are stretched to the limits.

Limitations

Due to the small sample size of this study findings need to be taken as preliminary results. The study was limited to participants from one pediatric hospital in Chicago, Illinois. Sample size was smaller than anticipated because of low patient census in the hospital. In addition, some fathers were hard to reach due to their work schedules or limited availability to come to the hospital for interviews. Also, most of the fathers

interviewed were Mexican which is not representative of the variety of groups in the Latino population. Having a small sample brings limitations to the generalizability of its findings and decreases the statistical power. This may have been a factor in the lack of correlation between the main variables.

One major limitation of relational studies is that while they look at how two variables relate to each other, there are many other unidentified and unknown variables that may also impact that relationship (moderating factors). Some possible moderating factors such as developmental stage, gender role transitions, family interaction patterns, interpersonal situations, level of acculturation, sexual orientation, fathers' health status, and peer relationships were not in the scope of this study. In addition, the study did not measure differences in treatment options such as experimental trials or having a stem cell transplant. The study also did not measure differences in diagnosis. Certain types of cancer have more reserved prognosis. This can have a varied effect on the patient and family experience.

Recommendations for Further Research

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. Considering that, mixed methods approach is a viable methodology when studying the topic (Greene, 2007). It is useful 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). One suggestion for further study

would be the inclusion of additional qualitative questions about the type of relationship fathers have with their spouses, how they manage the limitations of work and time off to provide caregiving, and adding more narrative stories of how fathers coped with the diagnosis of their child from early on until end of treatment.

More research is indicated to identify fathers' unique emotional, social, financial and health care roles and needs in family caregiving. Research needs to focus more on men as caregivers and fathering in contrast to the essentialist construction that equates ideal parenting to women. Research on fathers also needs to include the study of dual income earning families versus single earners in which the father or the mother is the sole breadwinner. In addition, it is pertinent to develop research on intergenerational perspectives such as the role of grandparents in caregiving and how their roles intersect fathers' care. The researcher also recommends the study of how fathers' previous experience of caregiving is related to their conceptions and role providing care in the present circumstances. Qualitative studies are also needed to explore fathers' own psychosocial development and how it determines their identity as men and the kind of care they provide. Special attention should be given to explore how the life stage when men enter fatherhood affects how they engage in caregiving. In addition, further studies can investigate the experience of single fathers' caregiving.

Longitudinal studies would also be valuable in capturing the experience of male caregiving over time. Additionally, differences between subsets of the population such as patients with brain tumors versus 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 the child's age on

parent outcomes requires research as there is only a small number of studies (Pai et al., 2007).

On the other hand, despite their common-sense appeal, the familiar group labels routinely used in United States' health research are in fact based on a confusing mix 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 Latino origin. Researchers often use terms such as "Hispanic" to confine 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). Thus, studying the nuances among the various groups within the Latino populations is important to help understand variation.

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 who provide care to children with cancer and other life-threatening illnesses. Gay fathers' perspectives would be valuable, "as they may also face additional stigmata in the health care systems that are not experienced by heterosexual fathers" (Wolff et al., 2011, p.155).

However, it is worth mentioning that attention to all men in society continues to be an area in need of research in social work. The research has been defined by an emphasis on women's studies, issues of domestic violence, and feminist topics. Any interest generated to study heterosexual men tends to focus on specific pathology or so-

called deviant behavior. The emphasis has been on studying men as abusers, homeless, HIV victims, prisoners, absent fathers, or on probation (Kosberg, 2015).

More needs to be done to understand men from multicultural backgrounds. While the focus of this study was on Latino fathers, it would be remiss to not suggest that providing services to any immigrant and/or refugee to the U.S. is an important consideration and an additional arena for study, especially from a social work perspective which is highly contextual and systemic, given the influx of immigrants and refugees to the U.S. over the past decade. Ethnic minorities and others may have difficulty with the language, particularly with medical terminology, or with fewer experiences in health care systems and with different cultural responses, and the patient and the family system would likely benefit from analysis of their situation and resultant needs.

Conclusion

Although women are often viewed as primary caregivers of children, contemporary social conditions are challenging men in the Latino community to assume an increasingly active role in raising children. It seems that the characterization of behaviors of Latino males as exclusively determined by the aggressive, authoritarian and stoic machismo may be inaccurate. This study explored the relationships between Latino fathers' masculine identity, caregiving and coping when faced with the demands generated by having a child diagnosed with cancer. The fathers in this study depart from the discourse of hegemonic masculinity, that is, one defined by the dominant stereotyped gender roles that prescribe how men ought to behave (Connell, 2005). Contrary to that construction, results from the study suggest an emerging trend among these men to move away from the rigid roles that prescribe how a man must behave as it relates to coping

and caregiving. Although the ideology of domesticity still permeates society, the fathers in the study may signal steps toward a redefinition of fatherhood and caregiving that is more contextual, anchored in an identity shaped by historical, economic, social and political realities and in tune with the demands of the present time and complex society.

Although results of the study cannot be generalized to the larger population, the data provides initial insight into how Latino men face the challenges of balancing social expectations about their role of caregivers, fathers and primary income earners. The study is an exploration into their role conflicts and how they resort to multiple strategies to help them cope with stressful demands. The study also highlights the centrality of the burden Latino fathers experience when they are split between prioritizing the needs of their child with cancer while also dealing with the demands of work responsibilities. This is not an easy position to be in as the fathers in the study indicate. However, they suggest a level of resilience and courage to thrive, or as some of them indicated, “to keep the fight” anchored in support from relatives, spouses, friends and others who they find reliable.

In this experience of caregiving many fathers re-imagine the meaning of life and cling to a spirituality that is full of optimism, hope and valor to face the hardship of their child’s diagnosis and feelings of sadness, isolation, despair and frustration. In the end, however, it becomes an experience of growth, change and survival as they accompany their child in what is one of the most difficult experiences a human being can face when confronted by the fragility of life and the uncertainty of what lies ahead as the child undergoes treatment. Considering this it is imperative for professionals in social work to be collaborators with healthcare providers to provide culturally-sensitive interventions,

assist in advocacy efforts, and the implementation of interventions and policies to support

Latino fathers who are caregiving children with cancer.

APPENDIX A
PARTICIPANT RECRUITMENT LETTER (ENGLISH & SPANISH VERSIONS)



Dear Mr. _____

My name is Noe Mojica, and I am a social worker at the Ann & Robert H. Lurie Children's Hospital of Chicago. I am leading a study with the Hematology/Oncology department titled: ***Men as Caregivers: Latino Fathering of Children with Cancer.***

The goal of this research is to learn more about Latino fathers and the care they give when they have children with cancer. The study will ask about fathers' stress, supports and challenges (if any) of giving care to their children who have cancer.

You have been selected as a potential participant because you are a father of a child who has cancer.

Should you agree to participate in the research an interview time will be scheduled. All interviews will take place at the Ann & Robert H. Lurie Hospital or on the phone. Interviews are expected to take between 45 minutes to 1 hour. You are free to end the interview at any time you wish. All data gathered in the course of the interview will be treated with confidentiality by the researcher.

Should you need additional information or if you have questions, please contact me at the following phone number: (312) 227-3291.

Noe Mojica



Estimado Sr. _____:

Mi nombre es Noe Mojica, y soy trabajador social en Ann & Robert H. Lurie Children's Hospital of Chicago. Estoy conduciendo un estudio en el Departamento de Hematología/Oncología, titulado: ***Los hombres a cargo de los pacientes: padres latinos de niños con cáncer***

El objetivo de esta investigación es aprender más acerca de los padres latinos y el cuidado que proporcionan cuando tienen hijos con cáncer. El estudio abarcará preguntas sobre el estrés que sienten los padres, así como el apoyo y los retos (si existen) que conlleva cuidar a sus hijos con cáncer.

Se le ha elegido como un posible participante debido a que usted es el padre de un(a) niño(a) con cáncer.

Si accede a participar en la investigación, se programará una entrevista. Todas las entrevistas se llevarán a cabo en Ann & Robert H. Lurie Children's Hospital of Chicago o por teléfono y se espera que tengan una duración de 45 minutos a 1 hora. Usted puede finalizar la entrevista en cualquier momento. Toda la información recabada durante la entrevista será tratada de manera confidencial por el investigador.

Si desea información adicional o tiene preguntas, comuníquese conmigo al número de teléfono: (312) 227-3291.

Muy atentamente,

Noé Mojica

Versión 4/30/14

APPENDIX B
CONSENT FORM (ENGLISH & SPANISH VERSIONS)

**ANN & ROBERT H. LURIE CHILDREN'S HOSPITAL OF CHICAGO
INSTITUTIONAL REVIEW BOARD
Adult Consent to Participate in a Research Project**

Investigators at Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's) invite you to consider participating in a research study entitled:

Men as Caregivers: Latino Fathering of Children with Cancer

This research is carried out by *Noe Mojica*. This researcher is an employee of Lurie Children's and a doctoral student at Loyola University Chicago. This project is part of his doctoral dissertation work to fulfill requirement for the PhD in Social Work. A dissertation is a study about a specific area of interest, for example, men as caregivers.

This consent form describes a study being done at Lurie Children's. Research studies help us learn more about conditions and possible new ways to give services to families. Research studies are voluntary, which means that it is your choice whether to participate in the study. The study staff will also explain the study to you and answer any questions that you may have before you make a decision.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to obtain knowledge about the relationship of Latino men and the care they give when they have children with cancer. The study will ask about fathers' stress, supports and challenges (if any) of giving care to their children who have cancer.

WHAT IS INVOLVED IN THE STUDY AND HOW LONG WILL I BE IN THE STUDY?

The study will include a total of 20 men who are fathers of children with cancer.

If you agree to be in the study, you will be asked to:

- Participate in an interview to answer a number of questions. The questions will cover areas related to your view of yourself as a man, stress level, supports, and activities you do with your child. It takes about one hour to answer all the questions.
- The interview will happen in the oncology clinic or the inpatient room. The researcher and you can decide if there is a different place you prefer to do the interview. You also have the option to have a phone interview if you are unable to have a face-to-face interview at the hospital.
- Interviews are expected to take between 45 minutes to 1 hour.

ARE THERE BENEFITS (GOOD THINGS) TO TAKING PART IN THE STUDY?

There are no direct benefits to you from taking part in this study. However, results from this study will help to develop more ways to aid Latino fathers who deal with the illness of their children.



WILL I BE TOLD ABOUT NEW INFORMATION?

We will tell you if we learn new information that may make you change your mind about being in this study.

WHAT ARE THE POSSIBLE RISKS OR SIDE EFFECTS (BAD THINGS) OF THE STUDY?

You may experience some emotional discomfort during the interview because some of the questions relate to your personal opinion and life. It is also very normal to feel sadness or other related emotions as you think about your child's illness, or other difficult experiences you've had with him or her. You may skip or not answer any question you do not want to answer. There is a potential loss of confidentiality, in order to lower this risk only study staff will have access to your study information.

WHAT OTHER OPTIONS ARE THERE?

You decide if you want to participate in the study. If you do not want to be in this study, you do not have to participate. Even if you decide to participate, you are free not to answer any question or to remove from participation at any time without bad consequences.

WHAT IF THE INVESTIGATOR OR I DO NOT THINK I SHOULD STAY ON THE STUDY?

You can decide to stop your participation at any time during the interview. Your decision to participate or not will not change the services that you and your child are currently receiving at Lurie Children's. The investigator may decide you should not stay in the study. He will explain to you the reasons if he thinks you should not stay on the study. This will not change the services you or your child is receiving at the hospital.

WHAT ARE THE COSTS?

You will not be charged for your participation on the study. There are no costs to you.

Lurie Children's may be able to provide some financial assistance to eligible patients. To obtain more information about this program ask your healthcare team or visit the website <http://luriechildrens.org/en-us/care-services/billing-medical-records/Pages/financial-assistance.aspx>.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

No, you will not receive payment for your participation.

WHAT DO I DO IF I AM INJURED?

There is minimal risk of injury for participating in the study as it will consist of a face-to-face or phone interview between you and the researcher. No drugs, treatments or devices will be used.



WHO WILL KNOW ABOUT WHAT I DID IN THE STUDY OR HAVE ACCESS TO MY PRIVATE INFORMATION?

This signed consent form will be placed in your medical record at Lurie Children's with a copy placed in the Principal Investigator's research file. Some or all of the research results may be included in your medical records. If you do not have a medical record at Lurie Children's, then this signed consent form will only be kept in the Principal Investigator's research file.

If you sign this consent form, you give permission for the researcher and Lurie Children's to provide the de-identified results of the study to the following people, agencies or companies to review and use in this research study:

- Lurie Children's study staff
- Lurie Children's Institutional Review Board (the committee that is in charge of protecting the rights of all adults and children who participate in research studies at Lurie Children's)
- Loyola University Chicago, Graduate School of Social Work

Lurie Children's and the researcher will keep the records of this study confidential, and will release the de-identified study information only to the people, organizations, or companies listed above. None of your personal medical information or your child's will be released to outside agencies, companies or persons. You will not be identified individually in any written or oral reports of this study to professionals or the media.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

By signing this consent form, you agree to take part in this study. You are not giving up any of your legal rights or releasing this hospital from responsibility for carelessness.

You may cancel your consent and take yourself out of this study at any time without penalty or loss of benefits. Your treatment by, and relations with the physician(s) and staff at Lurie Children's, now and in the future, will not be affected in any way if you refuse to take part, or if you enter into the study and then withdraw from it.

At any time, you can tell the researcher or Lurie Children's not to use or give out your study information to other people, organizations, or companies. Withdrawal of this permission must be in writing. Your decision will not change your child's medical treatment or other services received at Lurie Children's.

If you wish, you will be able to ask for this study research information when the study is over or when you are no longer taking part in the study. This does not affect your right to see your child's medical record or the results of tests related to regular medical care that is given during the same time as the research study.

Approved by IRB on 4/29/2015
 IRB Approval Expires on 3/31/2016
 Lurie Children's IRE 2014-15808

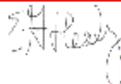


If you have any questions about the research methods, you should contact the researcher, Noe Mojica, by calling 312-227-3291 during a workday or leave a message at the confidential voicemail if you call during evening or night hours.

If you have any questions about your rights as a participant in a research study (research subject), wish to discuss problems, concerns, and questions, wish to obtain information, or wish to offer input to someone who is not directly involved with this study, you may contact Philip V. Spina, Sr. Vice-President and Chief Operating Office, Ann & Robert H. Lurie Children's Hospital of Chicago Research Center, 225 East Chicago Avenue, Box #205, Chicago, Illinois 60611. (Phone: (773)755.6301; Fax: (773)755. 6533; E-mail: pspina@luriechildrens.org).

You will be given a copy of this consent form.

Approved by IRB on 4/29/2015
IRB Approval Expires on 3/31/2016
Lurie Children's IRE: 2014-15808



SIGNATURES

The study has been explained to me and I have read this consent form, have been given the opportunity to consider my decision, and have had all my questions answered. I agree to take part in this study as explained in this consent form. I agree to let my doctor or Lurie Children's use and give out my health information in the way it is described in this consent form until the end of the research study.

 Date

 Signature of Participant (≥ 18 years)

 Printed Name of Research Subject or LAR

I certify that I have explained the above to the subject and believe that the signature(s) was affixed freely. I also agree to answer any questions that may arise.

 Date

 Signature of Person Obtaining Consent (PI or designee)

 Printed Name of Person Obtaining Consent (PI or designee)
INTERPRETER/WITNESS SIGNATURE:

By signing this consent and the translated short form, I attest that the elements of informed consent were presented verbally to the parent(s)/LAR in their native language. He/she was given the opportunity to have all questions answered. Consent was obtained freely as is indicated by his/her signature on the short form.

 Printed Name of Interpreter/Witness
May be the interpreter, but cannot be the same as the person obtaining consent.

 Signature of Interpreter/Witness
Or the unique ID# of the phone interpreter and his/her company name

**ANN & ROBERT H. LURIE CHILDREN'S HOSPITAL OF CHICAGO
COMITÉ DE EVALUACIÓN INSTITUCIONAL**

Consentimiento del adulto para participar en un estudio de investigación

Los investigadores del Ann & Robert H. Lurie Children's Hospital of Chicago (Lurie Children's) le invitan a considerar su participación en un estudio de investigación titulado:

Los hombres a cargo de los pacientes: padres latinos de niños con cáncer

Esta investigación es llevada a cabo por *Noe Mojica*. El investigador es empleado de Lurie Children's y un estudiante doctoral de la Universidad de Loyola en Chicago. Este proyecto es parte de su tesis doctoral para cumplir con los requerimientos para su doctorado en trabajo social. La tesis es un estudio sobre un área de interés específica, por ejemplo, los hombres a cargo de un paciente.

Este formulario de consentimiento describe un estudio llevado a cabo en Lurie Children's. Los estudios de investigación nos ayudan a aprender más sobre las enfermedades y sus posibles nuevos tratamientos; y son de carácter voluntario, lo que significa que usted decide si participa en ellos. El personal del estudio se lo explicará en detalle y le contestará toda pregunta que tenga antes de tomar su decisión.

¿POR QUÉ SE LLEVA A CABO ESTE ESTUDIO?

El propósito de este estudio es obtener información sobre la relación de los hombres latinos y el cuidado que proporcionan cuando tienen hijos con cáncer. En el estudio se harán preguntas sobre el estrés que sienten los padres, así como el apoyo y los retos (si existen) que conlleva cuidar a sus hijos con cáncer.

¿QUÉ IMPLICA EL ESTUDIO Y CUÁNTO TIEMPO DURARÁ MI PARTICIPACIÓN EN EL MISMO?

El estudio comprenderá un total de 20 hombres que son padres de niños con cáncer.

Si accede a participar en el estudio, le pediremos:

- Participar en una entrevista para contestar varias preguntas. Las preguntas abarcan temas relacionados a lo que opina de usted mismo como hombre, los niveles de estrés, el apoyo y actividades que realiza con su hijo(a). Contestar todas las preguntas se lleva alrededor de una hora.
- La entrevista se llevará a cabo en la clínica de Oncología o en la habitación del paciente en el hospital. Si lo prefiere, usted y el investigador podrán decidir cambiar el lugar de la entrevista. Si no puede presentarse en el hospital en persona, también tiene la opción de responder a la entrevista por teléfono.
- Se espera que las entrevistas duren entre 45 minutos y 1 hora.

¿EXISTEN BENEFICIOS (COSAS BUENAS) POR PARTICIPAR EN EL ESTUDIO?

Su participación en este estudio no le beneficiará directamente. Sin embargo, los resultados de este estudio ayudarán a generar diferentes maneras para ayudar a los padres latinos que deben enfrentar la enfermedad de sus hijos.

¿SE ME MANTENDRÁ AL TANTO DE LA INFORMACIÓN QUE VAYA SURGIENDO?

Lo pondremos al tanto de cualquier información que surja y que pudiera hacerle cambiar de parecer sobre su participación en este estudio.

¿CUÁLES SON LOS POSIBLES RIESGOS O EFECTOS SECUNDARIOS (COSAS MALAS) POR PARTICIPAR EN EL ESTUDIO?

Podría sentirse incómodo durante la entrevista debido a que algunas preguntas tratan de su opinión y vida personal. También es muy normal que sienta tristeza u otras emociones cuando esté pensando en la enfermedad de su hijo, o en otras experiencias difíciles que haya tenido con él o ella. No tiene que responder a las preguntas que no desee contestar. Existe la posibilidad de la pérdida de la confidencialidad, y para reducir dicho riesgo únicamente el personal del estudio tendrá acceso a su información del estudio.

¿SE BRINDAN OTRAS OPCIONES?

Usted decide si desea participar en el estudio. No tiene la obligación de participar en el mismo. Aun si decide participar, está en la libertad de no responder a cualquier pregunta o de retirarse cuando lo desee sin consecuencias perjudiciales.

¿QUÉ SUCEDE SI MI MÉDICO O YO NO CREEMOS QUE DEBA PERMANECER EN EL ESTUDIO?

Usted puede optar por dejar de participar en la entrevista en cualquier momento. Su decisión de participar no cambiará los servicios que usted y su hijo(a) reciben actualmente en Lurie Children's. El investigador podría determinar que usted no debe permanecer en el estudio, y en ese caso, le explicaría sus razones. Esto no cambiará los servicios que usted o su hijo(a) reciben en el hospital.

¿CUÁNTO CUESTA PARTICIPAR?

No se le cobrará por su participación en este estudio y esto tampoco implica costo alguno para usted.

Lurie Children's podría proporcionar algún tipo de asistencia financiera a los pacientes elegibles. El personal médico o clínico que le atiende, puede proporcionarle más información sobre este programa o usted mismo puede consultar el sitio: <http://luriechildrens.org/en-us/care-services/billing-medical-records/Pages/finacial-assistance.aspx>.

¿RECIBIRÉ ALGÚN TIPO DE COMPENSACIÓN POR PARTICIPAR?

No, no se le compensará por participar.

¿QUÉ DEBO HACER SI RESULTO LESIONADO(A)?

Existe un riesgo mínimo de lesión por participar en este estudio, ya que consiste de una entrevista en persona o por teléfono con el investigador. No se utilizarán ningún medicamento, tratamiento o dispositivo.

¿QUIÉN SABRÁ QUÉ FUE LO QUE HICE EN EL ESTUDIO O TENDRÁ ACCESO A MI INFORMACIÓN PRIVADA?

Una vez firmado, este formulario de consentimiento será archivado en su expediente médico en Lurie Children's y una copia se mantendrá en los archivos del Investigador Principal. Algunos o todos los resultados de la investigación podrían incluirse en su expediente médico. Si usted no tiene un expediente médico en Lurie Children's, este formulario de consentimiento, una vez firmado, se guardará únicamente en los archivos del Investigador Principal.

Al firmar este formulario de consentimiento, usted autoriza que el investigador y Lurie Children's proporcionen los resultados de este estudio desprovistos de información personal a las siguientes personas, organismos o compañías, para su revisión y uso en este estudio de investigación:

- El personal del estudio en Lurie Children's
- El Comité de Evaluación Institucional de Lurie Children's, encargado de proteger los derechos de todos los adultos y niños que participan en los estudios de investigación en Lurie Children's.
- La Facultad de Posgrado de Trabajo Social de la Universidad de Loyola en Chicago (Loyola University Chicago, Graduate School of Social Work)

Lurie Children's y el investigador mantendrán los expedientes del presente estudio de manera confidencial y divulgarán la información del estudio desprovista de datos personales solamente a las personas, organizaciones o compañías anteriormente indicadas. Usted no será identificado personalmente en ningún reporte oral o escrito de este estudio que se presente a otros profesionistas de la salud o a los medios.

¿CUÁLES SON MIS DERECHOS COMO PARTICIPANTE?

Al firmar este formulario de consentimiento, usted accede a participar en el presente estudio. Esto no significa que esté renunciando a ninguno de sus derechos legales ni eximiendo a este hospital de su responsabilidad en caso de negligencia.

Usted podrá cancelar su autorización y retirarse del presente estudio en cualquier momento, sin ninguna consecuencia ni pérdida de beneficios. El tratamiento que usted recibe y su relación con el (los) médico(s) y el personal de Lurie Children's no se verán afectados de ninguna manera ni

ahora ni en el futuro si usted se niega a participar en el estudio, o si se inscribe en el estudio y luego se retira del mismo.

Usted puede pedirle al investigador o a Lurie Children's en cualquier momento que no utilicen ni divulguen a otras personas, organizaciones o compañías su información recabada en el estudio. La cancelación de esta autorización deberá presentarse por escrito. Su decisión no afectará el tratamiento médico ni otros servicios que su hijo(a) recibe en Lurie Children's.

Si lo desea, podrá solicitar la información del estudio cuando éste haya concluido o cuando ya no esté participando en el mismo. Esto no afecta su derecho de consultar los expedientes médicos de su hijo(a) ni los resultados de los exámenes relacionados con la atención médica habitual que se le proporcione en el transcurso del estudio de investigación.

Si tiene preguntas sobre los métodos de investigación, debe contactar al investigador, Noe Mojica, llamándolo al 312-227-3291 durante días hábiles, o dejándole un mensaje en su correo de voz confidencial durante la tarde o la noche.

Si tiene alguna duda sobre sus derechos como participante en un ensayo clínico (sujeto de investigación), si desea hablar sobre algún problema, inquietud o pregunta, desea obtener información o darle su opinión a alguien que no esté directamente involucrado con este estudio, puede comunicarse con Philip V. Spina, Sr. Vice-President and Chief Operating Officer, Ann & Robert H. Lurie Children's Hospital of Chicago Research Center, 225 East Chicago Avenue, box #205, Chicago IL 60611. (Teléfono: 773.755.6301; Fax: 773.755. 6533; correo electrónico: pspina@luriechildrens.org).

Se le entregará una copia de este formulario de consentimiento.

FIRMAS

Se me ha explicado el estudio y he leído este formulario de consentimiento; se me ha dado la oportunidad de considerar mi decisión y se contestaron todas mis preguntas. Estoy de acuerdo en participar en este estudio de la manera descrita en este formulario de consentimiento. Autorizo que mi médico o Lurie Children's utilicen y divulguen mi información médica de la manera descrita en este formulario de consentimiento hasta que el estudio de investigación haya concluido.

Fecha

Firma del participante (18 años o mayor)

Nombre en letra de molde del sujeto de investigación o del LAR

Declaro que he explicado lo anterior al participante y considero que la(s) firma(s) fue(ron) suscrita(s) voluntariamente. También estoy de acuerdo en contestar cualquier pregunta que surja.

Fecha

Firma de la persona que obtiene el consentimiento (investigador principal o su representante)

Nombre en letra de molde de la persona que obtiene el consentimiento (investigador principal o su representante)



APPENDIX C
QUESTIONNAIRE (ENGLISH & SPANISH VERSIONS)

Men as Caregivers: Latino Fathering of Children with Cancer

Code # _____

Date: _____

DIRECTIONS: In this part I want to get to know you and get a little bit of background information about you. I am going to read each of the following questions. Please provide for each question one answer that best represents yourself or your opinion.

I. Background

1. What is your nationality?

Mexican
 Puerto Rican
 Cuban
 Dominican
 Argentinean
 Other(Specify)_____

2. What religion do you practice?

Christianity (Roman Catholic) Jewish Other (specify) _____
 Christianity (Protestant) Buddhist No religion
 Muslim Hindu

3. What is the highest school level you have achieved?

None Vocational or technical school Master
 1-4 a few years in college (no final degree) Doctorate
 5-8 Associate Degree Other (specify)_____

9-12 BA, BS, etc.

4. Marital status

Not married
 Married
 Widowed

___ Divorced

5. Do you and your child's mother live together?

___ Yes

___ No

6. What is your age? _____

7. How many children do you have including the child who is sick?

8. Family source of income (Check all that apply)

___ Salary

___ Own business

___ Social Security

___ Food Stamps

___ Other (specify) _____

9. Are you currently working? Specify what kind of job.

10. Does your wife or significant other works? Specify what kind of job.

11. What is the gender of your child with illness?

___ Male

___ Female

12. How old is he/she?

13. Do you have other children with a serious or chronic illness? Specify condition.

___ No condition Diagnosis _____

14. Where do you live?

___ Chicago
 ___ Suburbs
 ___ Far from suburban/metropolitan area

II. Caregiver's Coping (The following questions are related to how you deal with your stress and your concerns as a father and caregiver of a child who is seriously ill).

Please think of one particular stressful situation regarding your child that you have experienced and answer the following statement with how you reacted at the time. There is no right or wrong answer to each statement; your own reaction is what is asked for.

For each statement I am going to read to you :

0=Not Used, 1=Used Somewhat, 2=Used Quite a Bit, 3=Used a Great Deal

- ___ 15. Just concentrated on what I had to do next – the next step.
- ___ 16. I tried to analyze the problem in order to understand it better.
- ___ 17. Turned to work or substitute activity to take my mind off things.
- ___ 18. I felt that time would make a difference – the only thing to do was to wait.
- ___ 19. Bargained or compromised to get something positive from the situation.
- ___ 20. I did something which I didn't think would work, but at least I was doing something.
- ___ 21. Tried to get the person responsible to change his or her mind.
- ___ 22. Talked to someone to find out more about the situation.
- ___ 23. Criticized or lectured myself.
- ___ 24. Tried not to burn my bridges, but leave things open somewhat.
- ___ 25. Hoped a miracle would happen.

- _____ 26. Went along with fate; sometimes I just have bad luck.
- _____ 27. Went on as if nothing had happened.
- _____ 28. I tried to keep my feelings to myself.
- _____ 29. Looked for the silver lining, so to speak; tried to look on the bright side of things.
- _____ 30. Slept more than usual.
- _____ 31. I expressed anger to the person(s) who caused the problem.
- _____ 32. Accepted sympathy and understanding from someone.
- _____ 33. I told myself things that helped me to feel better.
- _____ 34. I was inspired to do something creative.
- _____ 35. Tried to forget the whole thing.
- _____ 36. I got professional help.
- _____ 37. Changed or grew as a person in a good way.
- _____ 38. I waited to see what would happen before doing anything.
- _____ 39. I apologized or did something to make up.
- _____ 40. I made a plan of action and followed it.
- _____ 41. I accepted the next best thing to what I wanted.
- _____ 42. I let my feelings out somehow.
- _____ 43. Realized I brought the problem on myself.
- _____ 44. I came out of the experience better than when I went in.
- _____ 45. Talked to someone who could do something concrete about the problem.
- _____ 46. Got away from it for a while; tried to rest or take a vacation.
- _____ 47. Tried to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.
- _____ 48. Took a big chance or did something very risky.
- _____ 49. I tried not to act too hastily or follow my first hunch.
- _____ 50. Found new faith.
- _____ 51. Maintained my pride and kept a stiff upper lip.
- _____ 52. Rediscovered what is important in life.

- _____ 53. Changed something so things would turn out all right.
- _____ 54. Avoided being with people in general.
- _____ 55. Didn't let it get to me; refused to think too much about it.
- _____ 56. I asked a relative or friend I respected for advice.
- _____ 57. Kept others from knowing how bad things were.
- _____ 58. Made light of the situation; refused to get too serious about it.
- _____ 59. Talked to someone about how I was feeling.
- _____ 60. Stood my ground and fought for what I wanted.
- _____ 61. Took it out on other people.
- _____ 62. Drew on my past experiences; I was in a similar situation before.
- _____ 63. I knew what had to be done, so I doubled my efforts to make things work.
- _____ 64. Refused to believe that it had happened.
- _____ 65. I made a promise to myself that things would be different next time.
- _____ 66. Came up with a couple of different solutions to the problem.
- _____ 67. Accepted it, since nothing could be done.
- _____ 68. I tried to keep my feelings from interfering with other things too much.
- _____ 69. Wished that I could change what had happened or how I felt.
- _____ 70. I changed something about myself.
- _____ 71. I daydreamed or imagined a better time or place than the one I was in.
- _____ 72. Wished that the situation would go away or somehow be over with.
- _____ 73. Had fantasies or wishes about how things might turn out.
- _____ 74. I prayed.
- _____ 75. I prepared myself for the worst.
- _____ 76. I went over in my mind what I would say or do.
- _____ 77. I thought about how a person I admire would handle this situation and used that as a model.
- _____ 78. I tried to see things from the other person's point of view.
- _____ 79. I reminded myself how much worse things could be.
- _____ 80. I jogged or exercised.

III. The Care of My Child with Cancer

Parents put some time and effort into taking care of their child with cancer. I want to better understand how much effort certain tasks require. Please indicate the amount of effort during the past week that these tasks have required of you. There is no right or wrong answer to each statement; your own reaction is what is asked for.

For each statement I am going to read to you:

0=did not do 1= less than 1 hour/week 2= 1-2 hours/week 3= 3-5 hours/week 4= more than 5 hours/week

Physical care

- ___ 81. Preparing and giving medicines, fluids and TPN (nutrition) intravenously (IV). (Preparation includes: tubing, pumps, drawing up medications).
- ___ 82. Preparing and giving medicine as a shot in the muscle (IM) or under the skin (SQ) (This includes: drawing up medications, applying EMLA cream).
- ___ 83. Preparing and giving medications by mouth (examples include: braking up pills, disguising taste, etc.).
- ___ 84. Preparing and giving catheter flushes.
- ___ 85. Changing the dressing on your child's catheter (i.e. Broviac, Hickman, port, etc.).
- ___ 86. Managing side effects of cancer or its treatment (examples includes: vomiting, mouth sores, diarrhea, frequent voiding/diaper changing).
- ___ 87. Keeping your child comfortable and without pain.
- ___ 88. Managing other childhood illnesses for your child with cancer (examples include: cold, flu, ear infections, other).
- ___ 89. Managing unexpected events related to your child's illness (Examples include: admission for fever, unscheduled appointment for blood transfusion, changes in treatment schedule because of low blood counts).
- ___ 90. Additional household tasks related to your child' illness (examples include: cleaning and maintenance of equipment, etc.).

___ 91. Coordinating, arranging, and managing medical services (examples include: scheduling appointments, locating equipment and negotiating services).

___ 92. Travel to and from the hospital for medical care.

___ 93. Time spent at the hospital for appointments (examples include: oncology, neurology, radiation oncology, surgery clinic, scans, and other tests).

Emotional Care

___ 94. Providing emotional support for your child with cancer.

___ 95. Providing emotional support for other children in the family.

___ 96. Providing emotional support for the extended family (examples include: grandparents, aunts, uncles, friends, etc.).

___ 97. Providing emotional support for your spouse/partner.

___ 98. Meeting your own emotional support needs.

___ 99. Comforting your child through the pain of the cancer and its treatment (examples include: procedures, mouth sores, bone pain, etc.).

___ 100. Taking care of discipline and/or behavior problems of the child with cancer (crying, irritability, moodiness).

Finances

___ 101. Taking care of finances, bills, and forms related to the child's illness.

Family / Interpersonal Relationships

___ 102. Planning activities for your child with cancer around the treatment and illness (examples include: school, playtime, rest, things for the child to do, other).

___ 103. Planning activities with your family around the treatment and illness (examples include; recreation, vacation, school functions, other).

___ 104. Getting child care / babysitting help for your ill child.

___ 105. Obtaining child care/ babysitting for brothers and sisters of the ill child.

___ Other (specify)_____

IV. Masculinity (The following questions are related to how you view yourself as a man, your ideas about it, and your responsibilities). Please indicate the number that most closely represents the degree that you agree or disagree with the statement. There is no right or wrong answer to each statement; your own reaction is what is asked for.

Strongly Agree						Strongly Disagree
6	5	4	3	2	1	

___ 111. Moving up the career ladder is important to me.

___ 112. I have difficulty telling others I care about them.

___ 113. Verbally expressing my love to another man is difficult for me.

___ 114. I feel torn between my hectic work schedule and caring for my health.

___ 115. Making money is part of my idea of being a successful man.

___ 116. Strong emotions are difficult for me to understand.

___ 117. Affection with other men makes me tense.

___ 118. I sometimes define my personal value by my career success.

___ 119. Expressing feelings makes me feel open to attack by other people.

___ 120. Expressing my emotions to other men is risky.

___ 121. My career, job, or school affects the quality of my leisure or family life.

___ 122. I evaluate other people's value by their level of achievement and success.

___ 123. Talking about my feelings during sexual relations is difficult for me.

___ 124. I worry about failing and how it affects my doing well as a man.

___ 125. I have difficulty expressing my emotional needs to my partner.

Strongly Agree						Strongly Disagree
6	5	4	3	2		1
___						126. Men who touch other men make me uncomfortable.
___						127. Finding time to relax is difficult for me.
___						128. Doing well all the time is important to me.
___						129. I have difficulty expressing my tender feelings.
___						130. Hugging other men is difficult for me.
___						131. I often feel that I need to be in charge of those around me.
___						132. Telling others of my strong feelings is not part of my sexual behavior.
___						133. Competing with others is the best way to succeed.
___						134. Winning is a measure of my value and personal worth.
___						135. I often have trouble finding words that describe how I am feeling.
___						136. I am sometimes hesitant to show my affection to men because of how others might perceive me.
___						137. My needs to work or study keep me from my family or leisure more than I would like.
___						138. I strive to be more successful than others.
___						139. I do not like to show my emotions to other people.
___						140. Telling my partner my feelings about him/her during sex is difficult for me.
___						141. My work or school often disrupts other parts of my life (home, family, health leisure).
___						142. I am often concerned about how others evaluate my performance at work or school.
___						143. Being very personal with other men makes me feel uncomfortable.
___						144. Being smarter or physically stronger than other men is important to me.
___						145. Men who are overly friendly to me make me wonder about their sexual

preference (men or women).

___ 146. Overwork and stress caused by a need to achieve on the job or in school, affects/hurts my life.

___ 147. I like to feel superior to other people.

V. In this section there are few questions about your child and his/her illness.

148. How long ago was your child diagnosed?

___ 3 months- 5months ago

___ 6- 8 months ago

___ 9 -12 months ago

___ >1 year but < 2 years

___ >2 years but <3 years

___ >3 years

149. What was your initial emotion(s) when you got the news of the diagnosis? (Participant may answer more than one).

___ Confused

___ Other (specify)_____

___ Angry

___ Sad

___ Hopeless

___ Guilty

___ Afraid

___ Skeptical, did not believe it

150. When you think about your son/daughter illness, how do you feel today?

Check all that apply.

___ Confused

___ Angry

___ Hopeful

___ Happy

___ Sad

___ Hopeless

___ Guilty

___ Optimistic

___ Afraid

___ Skeptical, did not believe it

151. What did you find most helpful during your visits or stays in the hospital with your child?

152. What do you think are your most important responsibilities as a father?

153. As a father, what would you like to tell other fathers who find out their child is seriously ill? What advice would you like to give them?

Thank you!

Notes

Los hombres a cargo de los pacientes: padres latinos de niños con cáncer

Código # _____

Fecha: _____

INSTRUCCIONES: En esta parte queremos conocerle y obtener un poco de información sobre sus antecedentes. Le leeré cada de una de las siguientes preguntas, para las cuales deberá proporcionar la respuesta que mejor le represente a usted o su opinión.

I. Antecedentes

1. ¿Cuál es su nacionalidad?

- mexicana
 puertorriqueña
 cubana
 dominicana
 argentina
 otra (especifique) _____

2. ¿Qué religión practica?

- cristianismo (católico romano) judaísmo otra(especifique)____
 cristianismo (protestante) budismo no practico ninguna
 islamismo hinduismo

3. ¿Cuál es su escolaridad máxima?

- ninguna escuela vocacional o técnica maestría
 1-4 unos años en la universidad (sin licenciarme) doctorado
 5-8 diplomado otra (especifique)_____
 9-12 licenciatura, ingeniería, etc.

4. Estado civil

- no estoy casado
 casado
 viudo

- ____divorciado
5. ¿Viven juntos usted y la madre del (de la) niño(a)?
____sí
____no
6. ¿Cuál es su edad? _____
7. ¿Cuántos hijos tiene, incluyendo su hijo(a) que está enfermo(a)? _____
8. Fuente del ingreso familiar (marque todas las que correspondan)
____salario
____negocio propio
____seguridad social
____vales para despensa (*food stamps*)
____otra (especifique) _____
9. ¿Trabaja actualmente? Especifique su trabajo:

10. ¿Su esposa o pareja trabaja? Especifique su trabajo:

11. ¿Cuál es el sexo de su hijo(a) enfermo(a)?
__masculino __femenino
12. ¿Qué edad tiene él o ella? _____
13. ¿Tiene otros hijos con enfermedades graves o crónicas? Especifique cuál:

___ No tienen afecciones

Diagnóstico _____

14. ¿Dónde vive?

___ Chicago

___ suburbios

___ lejos del área metropolitana

II. “Modos de Enfrentar”

(una situación difícil la cual nos causa estrés)

Las siguientes declaraciones están relacionadas con la forma de enfrentar el estrés y las preocupaciones como padre que brinda cuidado a un niño/a que tiene una enfermedad muy difícil. Por favor, piense en una situación que le cause estrés relacionada con su hijo/a y conteste cada una de las siguientes declaraciones e indique, cómo usted reaccionó en ese momento. No hay respuestas correctas o incorrectas; sólo pedimos que nos dé su opinión.

Por cada declaración que le lea (conteste):

0=no lo hice 1= la utilicé un poco 2= la utilicé bastante 3= la utilicé muchísimo

___ 15. Me concentré exclusivamente en lo próximo que tenía que hacer, en el próximo paso.

___ 16. Traté de analizar el problema para entenderlo mejor.

___ 17. Me concentré en el trabajo u otra actividad para alejar mi mente del problema.

___ 18. Sentí que el tiempo haría una diferencia. Lo único que había que hacer era esperar.

___ 19. Me propuse a obtener algo positivo de la situación.

___ 20. Hice algo que pensé no iba a funcionar, pero al menos hice algo.

___ 21. Intenté encontrar a la persona responsable para hacerla cambiar de idea.

___ 22. Hablé con alguien para saber más sobre la situación.

___ 23. Me critiqué y me reprendí a mí mismo.

___ 24. Traté de no agotar todas mis posibilidades, sino que dejé alguna posibilidad abierta.

___ 25. Esperé que ocurriera un milagro.

- _____ 26. Seguí adelante con mí destino; simplemente a veces tengo mala suerte.
- _____ 27. Seguí adelante como si no hubiese pasado nada.
- _____ 28. Traté de guardar mis sentimientos para mí mismo.
- _____ 29. Busqué algún indicio de esperanza, por así decirlo; intenté mirar el lado bueno de las cosas.
- _____ 30. Dormí más de lo común.
- _____ 31. Le dejé saber a la persona (as) que causaron el problema lo molesto (a) que estaba.
- _____ 32. Acepté el entendimiento y la comprensión de alguien.
- _____ 33. Me dije a mí mismo cosas que me ayudaron a sentir mejor.
- _____ 34. Me sentí inspirado(a) para hacer algo con creatividad.
- _____ 35. Traté de olvidarme de todo.
- _____ 36. Busqué la ayuda de un profesional.
- _____ 37. Cambié o maduré como persona.
- _____ 38. Esperé a ver lo que pasaba antes de hacer algo.
- _____ 39. Me disculpé o hice algo para remediar.
- _____ 40. Desarrollé un plan de acción y lo seguí.
- _____ 41. Lo que yo quería no fue posible así que acepté otra mejor posibilidad.
- _____ 42. De algún modo dejé saber cómo me sentía.
- _____ 43. Me di cuenta de que yo fui la causa del problema.
- _____ 44. La experiencia me vino muy bien; salí mejor de lo que estaba antes.
- _____ 45. Hablé con alguien que podía hacer algo específico sobre el problema.
- _____ 46. Me alejé del problema por un tiempo; traté de descansar o tomarme unas vacaciones.
- _____ 47. Traté de sentirme mejor ya sea comiendo, tomando, fumando, usando drogas o medicamentos, etc.
- _____ 48. Aproveché la oportunidad e hice algo muy arriesgado.
- _____ 49. Traté de no actuar apresuradamente o dejarme llevar por mi primer impulso. (intuición)

- _____ 50. Encontré fe en algo nuevo.
- _____ 51. Mantuve mi orgullo y conservé el valor.
- _____ 52. Volví a descubrir lo que es importante en la vida.
- _____ 53. Cambié algo para que las cosas salieran bien.
- _____ 54. En general, evité estar con la gente.
- _____ 55. No permití que me afectara; me rehusé a pensar demasiado en el problema.
- _____ 56. Pedí consejo a un familiar o amigo a quien respeto.
- _____ 57. Evité que otros supieran lo mal que iban las cosas.
- _____ 58. No le di mucha importancia a la situación; me negué a tomarla demasiado en serio.
- _____ 59. Hablé con alguien acerca de cómo me sentía.
- _____ 60. Me mantuve firme y peleé por lo que quería.
- _____ 61. Me desquité con los demás.
- _____ 62. Recurrí a mis experiencias pasadas; ya me había encontrado en una situación parecida.
- _____ 63. Supe lo que había que hacer, así que redoblé mis esfuerzos para que las cosas marcharan bien.
- _____ 64. Me negué a creer lo que había ocurrido.
- _____ 65. Me prometí a mí mismo(a) que la próxima vez las cosas serían diferentes.
- _____ 66. Se me ocurrieron un par de soluciones diferentes para resolver el problema.
- _____ 67. Lo acepté, ya que nada se podía hacer al respecto.
- _____ 68. Traté de evitar que mis sentimientos interfirieran demasiado con otras cosas.
- _____ 69. Deseé poder cambiar lo que había sucedido o como me había sentido.
- _____ 70. Cambié algo de mí mismo.

- _____ 71. Soñé o me imaginé un tiempo o lugar mejor que en el cual me encontraba.
- _____ 72. Deseé que la situación desapareciera o terminara de algún modo.
- _____ 73. Tuve fantasías o deseos acerca de cómo deberían salir las cosas.
- _____ 74. Rezé.
- _____ 75. Me preparé para lo peor.
- _____ 76. Repasé en mi mente lo que haría o diría.
- _____ 77. Pensé de la manera en que una persona a quien admiro manejaría la situación y seguí su ejemplo.
- _____ 78. Traté de ver las cosas desde el punto de vista de la otra persona.
- _____ 79. Me recordé a mí mismo que las cosas podrían estar peor.
- _____ 80. Me fui "jogging" o hice otro tipo de ejercicio.

III. El cuidado de mi hijo(a) con cáncer

Los padres consumen tiempo y esfuerzo cuando cuidan de un(a) hijo(a) que tiene cáncer. Me gustaría comprender mejor cuánto esfuerzo requieren ciertas tareas. Por favor indique cuánto esfuerzo le llevó durante la semana pasada realizar estas tareas. No hay respuestas correctas o incorrectas; sólo pedimos que nos dé su opinión.

Por cada declaración que le lea (conteste):

0=no lo hice 1= menos de 1 hora a la semana 2= 1–2 horas a la semana 3= 3-5 horas a la semana 4= más de 5 horas a la semana

Atención física

- _____ 81. Preparar y administrar medicamentos, suero y nutrición parenteral total (TPN) por vía intravenosa (IV). (La preparación incluye: sondas, bombas, medir los medicamentos).
- _____ 82. Preparar y administrar medicamento inyectado en el músculo (IM, intramuscular) o debajo de la piel (SQ, subcutáneo). (Esto implica: medir los medicamentos, aplicar la crema analgésica *EMLA*).
- _____ 83. Preparar y administrar medicamentos por vía oral (por ejemplo: partir pastillas, tratar de ocultar el mal sabor del medicamento, etc.)
- _____ 84. Preparar y administrar las soluciones para enjuagar el catéter.

- ___ 85. Cambiar el vendaje del catéter de su hijo(a) (por ejemplo: Broviac, Hickman, port, etc.)
- ___ 86. Controlar los efectos secundarios del cáncer y su tratamiento (por ejemplo: el vómito, llagas en la boca, diarrea, micción frecuente o cambios de pañal).
- ___ 87. Mantener cómodo(a) y sin dolor a su hijo(a).
- ___ 88. Controlar otras enfermedades de la niñez cuando su hijo(a) tiene cáncer (por ejemplo: resfriados, influenza, infecciones de oído, otras).
- ___ 89. Controlar sucesos inesperados relacionados a la enfermedad de su hijo(a), (por ejemplo: hospitalizaciones por fiebre, citas de último minuto por transfusiones de sangre, cambios en el calendario de tratamiento debido a un conteo sanguíneo bajo).
- ___ 90. Quehaceres de la casa adicionales a la enfermedad de su hijo(a), (por ejemplo: limpieza y mantenimiento de equipo, etc.).
- ___ 91. Coordinación, programación y administración de servicios médicos (por ejemplo: programar citas, localizar equipo y negociar servicios).
- ___ 92. Transportarse de ida y vuelta al hospital para su atención médica.
- ___ 93. Tiempo pasado en el hospital para sus citas (por ejemplo: oncología, neurología, radiación, clínica de cirugía, imágenes médicas y otras pruebas).

Atención emocional

- ___ 94. Proporcionarle apoyo emocional a su hijo(a) con cáncer.
- ___ 95. Proporcionarle apoyo emocional a otros niños en la familia.
- ___ 96. Proporcionarle apoyo emocional a parientes (como: abuelos, tías, tíos, amigos, etc.).
- ___ 97. Proporcionarle apoyo emocional al cónyuge o pareja.
- ___ 98. Cubrir sus propias necesidades de apoyo emocional.
- ___ 99. Reconfortar a su hijo(a) durante el dolor del cáncer y su tratamiento (por ejemplo: durante intervenciones, si tiene llagas en la boca, dolor de huesos, etc.).

- ____ 100. Poner atención a problemas de disciplina o comportamiento del niño con cáncer (llanto, irritabilidad, cambios en su estado de ánimo).

Economía

- ____ 101. Encargarse de la economía del hogar, pagar cuentas y contestar formularios relacionados a la enfermedad del (de la) niño(a).

Relaciones familiares e interpersonales

- ____ 102. Planear actividades para su hijo(a) con cáncer dependiendo de la enfermedad y su tratamiento (por ejemplo: escuela, juego, descanso, cosas que hacer para entretenerse, entre otras).
- ____ 103. Planear actividades para usted y su familia dependiendo de la enfermedad y el tratamiento (por ejemplo: actividades recreativas, vacaciones, eventos en la escuela, otros).
- ____ 104. Buscar quién pueda cuidar de su hijo o ayuda para cuidar de su hijo(a) enfermo.
- ____ 105. Buscar quién pueda cuidar de los hermanos o hermanas del (de la) niño(a) enfermo(a).

Comunicación

- ____ 106. Comunicar la información sobre el cáncer a la escuela, guardería, niños, parientes y amigos.
- ____ 107. Observar y reportar los síntomas físicos y el estado médico de su hijo(a) al equipo médico.
- ____ 108. Obtener información acerca de la enfermedad y el tratamiento de su hijo(a), (por ejemplo: en la biblioteca, por parte del equipo médico, organizaciones en la comunidad).
- ____ 109. ¿Hay algo más que desee informarnos respecto al cuidado de su hijo(a) con cáncer?

110. ¿Con quién puede contar usted más para que le ayude? ¿Quiénes son las 3 personas más importantes en su situación?

___ mi esposa

___ mis parientes (tía, abuela, primos, hermanos, etc.)

___ mis amigos

___ mi pastor, mi párroco o líder espiritual

___ mis colegas

___ el trabajador social de mi hospital

___ mi consejero/terapeuta

___ otra (especifique) _____

144. Es importante para mí ser más inteligente o más fuerte físicamente que otros hombres.
145. Los hombres que son demasiado amigables conmigo me hacen dudar de su preferencia sexual.
146. El exceso de trabajo y el estrés que me produce la necesidad de tener logros en el trabajo o la escuela, afectan o lastiman mi vida.
147. Me gusta sentirme superior a otras personas.

V. En esta sección se encuentran unas preguntas acerca de su hijo(a) y su enfermedad.

148. ¿Hace cuánto fue diagnosticado(a) su hijo(a)?

- 3 – 5 meses
- 6 – 8 meses
- 9 – 12 meses
- más de 1 año, pero menos de 2
- más de 2 años, pero menos de 3
- más de 3 años

149. ¿Qué sintió inicialmente cuando recibió la noticia del diagnóstico? (Puede elegir más de una opción).

- confusión otra (especifique) _____
- enojo
- tristeza
- desesperanza
- culpa
- miedo
- escepticismo, no lo creía

150. Cuando piensa en la enfermedad de su hijo(a), ¿qué siente el día de hoy? Marque todas las opciones que correspondan:

- confusión
- enojo
- esperanza
- felicidad
- tristeza
- desesperanza

- culpa
- optimismo
- miedo
- escepticismo, no lo creía

151. ¿Qué piensa que fue lo más útil durante sus visitas o estancias en el hospital con su hijo(a)?

152. Como padre, ¿cuáles piensa que son sus responsabilidades más importantes?

153. Como padre, ¿qué le gustaría decirle a otros padres de familia que se enteran de que su hijo(a) padece una enfermedad grave? ¿Qué consejo les daría?

¡Gracias!

Notes

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VITA

Noe Mojica was born and raised in Puerto Rico. He is a licensed clinical social worker in the State of Illinois with more than 20 years of experience in the practice of social work. He has served in various roles in areas of community organizing, intervention with families, and individuals, child protection, and pediatric healthcare. He holds a Bachelor of Arts Degree in Social Sciences and a Master's Degree in Social Work, both from the University of Puerto Rico. In addition, he obtained a Master of Divinity Degree from McCormick Theological Seminary. He has published in peer-reviewed journals in the areas of grief, spirituality and fathering and caregiving. His research interests include social work with diverse populations, masculinities, grief and loss, spirituality, pediatric healthcare, and supervision in social work.