Photovoice with Pediatric Cancer Parents: Understanding Difficulties and Communicative Behaviors for Coping Effectively

Gabriela Isela Morales

University of Texas at El Paso, gabmo17@gmail.com

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PHOTOVOICE WITH PEDIATRIC CANCER PARENTS: UNDERSTANDING DIFFICULTIES AND COMMUNICATIVE BEHAVIORS FOR COPING EFFECTIVELY

GABRIELA ISELA MORALES

Department of Communication

APPROVED:

___________________________________________
Arvind Singhal, Ph.D., Chair

___________________________________________
Stacey K. Sowards, Ph.D.

___________________________________________
Lucía Durá, Ph.D.

Benjamin C. Flores, Ph.D.
Interim Dean of the Graduate School
PHOTOVOICE WITH PEDIATRIC CANCER PARENTS: UNDERSTANDING
DIFFICULTIES AND COMMUNICATIVE BEHAVIORS FOR COPING EFFECTIVELY

By

GABRIELA ISELA MORALES

THESIS

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Abstract

Pediatric cancer is a disease that not only affects children but their families as well. Both patients and their caregiving families have to cope with the many twists and turns that every day presents. This research study is aimed to understand and discover through the use of Photovoice—responding to questions through photographs and later narrating them—what difficulties and dilemmas parents face and what communicative behaviors and practices parents engage in to effectively care for their child. Living effectively with pediatric cancer involves more than medical regimens and treatment schedules. How this disease is communicated in public discourses, and how caregivers communicate with their children, the medical staff, and with family and friends plays an important role in how effective coping can occur.

Pediatric cancer parents involved with Candlelighters, an organization that helps children with cancer and their families, were recruited to be part of the study. The only requirement was for participants to be parents of children who had gone or were currently undergoing treatment for any type of cancer. Twelve participants were chosen for this study and asked to photograph, in one week, communicative behaviors and practices that they believed answered how they were able to effectively cope with their child’s cancer. Narrations were then scheduled so participants could individually discuss the significance of the photos taken.

Parents emphasized the importance of recording their journey through pediatric cancer. While parents faced communicative difficulties and dilemmas as a result of public ignorance, or not being able to fully count on their spouses for support, they found solace in focusing on their child’s care and in ensuring their wellbeing. Emphasizing play with artifacts like dolls and tricycles offered both the parent and the child a level of comfort. A pro-active follow-up approach involving being on top of treatment regimens and following through with medical staff
was utilized by some to feel a degree of control in caregiving. This also led parents to engage in sharing their experiences with other parents and solving any potential problems by being verbally pro-active. Parents also emphasized honest communication among them and their children in order to keep building and maintaining a strong relationship. Parents were able to effectively deal with the emotional and affective aspects of caregiving by communicating with others for support, receiving help and guidance from family members, being cared for by “surrogate” family (e.g., hospital staff), and practicing one’s faith.
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Preface

Deciding on what topic to focus on for my thesis was a challenge for me. I have many distinct interests and narrowing to one in particular was difficult. After learning about many new concepts and methods like Photovoice, Positive Deviance, Liberating Structures, and others I was deliberating how these methods could serve those who were dealing with cancer. Since my mother’s breast cancer diagnosis over a decade ago, and her passing, I became acutely aware of the disease and how it affected caregivers, friends, and family members. After years of struggling to comprehend all the implications that come with the cancer diagnosis of a loved one, I seemed to have pushed it to the back of my mind, never thinking that anything positive would come from it.

It was not until I became a graduate student that the thought of doing research on cancer came into sharper focus. During my graduate courses, I purposely worked on projects pertaining to health issues, especially dealing with women and cancer. In Fall 2011, I participated in a Media Changemakers class at UTEP, and became aware of how different media had the potential to uncover cancer in different ways. I volunteered to be part of a video project for the El Paso-based Candlelighters, an organization that supports families with pediatric cancer. I wanted to face my fears head-on, and to see if I could truly do what I had set my sights on doing, i.e., research on some aspect of communication and cancer.

The video project allowed me an opportunity to work with cancer-stricken families, and to see the power of personal stories in discerning how caregivers coped with a cancer diagnosis of a loved one, and mustered support for treatment and rehabilitation. My thesis advisor, Dr. Arvind Singhal, encouraged me to dig deeper, allowing me to see that something good and empowering could rise from a seemingly devastating ordeal. With his encouragement and the
emotional support of my father and my significant other, I ventured into the world of cancer once again, this time focusing exclusively on caregiving parents of children with pediatric cancer.

My first task was to read literature on pediatric cancer. Many of the studies found focused on the afflicted child and their caregiving families and what they think about cancer and how they handle it. Almost all studies employed a personal interview, survey, or in-depth interviews. Reading these studies made me feel that the emotional component of coping with cancer was somehow lost in the sense-making. Around this time, Dr. Singhal suggested that I look at the method of Photovoice to gain richer, deeper insights from respondents. I had heard of Photovoice before, even read about it, but never did I consider this would make it into my final thesis project as the primary method of collecting data. After reading more about Photovoice, I began to grasp why Photovoice would be suitable as a method of data-collection, especially with a sensitive and gut-wrenching topic like cancer. In my mind, I could see how effective a photograph could be to break ice with the participants. I also could see how I would have an opportunity to narrate my own struggles with cancer caregiving, allowing for a deeper trust to build between the participants and me, and a richer sharing of ideas and experiences.

I was privileged to be invited to many events that Candlelighters, an organization that works with children with cancer and their families, hosted in the city of El Paso, notably the Valentine’s Day Dance, fund raising marches, and others. Participating in these events allowed me an opportunity to get to know more parents than the ones that were eventually involved with my study. They all expressed gratitude and even dared to say that it was about time someone asked them how they go about their day. “This can help others,” several of them noted.

I realized how emotionally-challenging such work could be, but I did not need to second guess myself. The enthusiasm of the parents got me on board fully. I found myself relating to
their stories—their triumphs, their struggles and fears. I was once where they stood—confused and constantly asking myself “Why?” The research process alleviated some of the weight such questions necessarily carry.

The photos that the respondents took were insightful and beautiful. The accompanying narrations were rich. We saw each other’s lives reflected back in still photographs. It was an eye-opening experience for all of us.
Chapter 1

Introduction

“My child wasn’t the only one going through cancer—I went through it too.”

-Anonymous

We usually associate children with qualities such as happiness, innocence, energy, curiosity, non-judgment, and more. One expects children to be running around, playing with friends and scraping their knees, nothing that antiseptic ointment and bandages cannot fix. These perceptions can lead family members to assume that when their child insists on having pain in their legs, arms, back, etc., or shows symptoms of nausea or fatigue, the child has come down with a temporary illness (Calderón-Guzmán et al., 2009). That these symptoms could indicate a pediatric cancer diagnosis is not a usual conclusion. After all, why would such a malady affect one’s child?

Due to the common everyday symptoms that most pediatric cancer patients present, late detection is common (Calderón-Guzmán et al., 2009). Once the grim diagnosis of pediatric cancer becomes real, the struggles are enormous for parents and the affected child. The present study analyzes the difficulties parents experience once their child is diagnosed with cancer, and identifies communicative behaviors and practices that parents, caregivers, and providers engage in that they believe to be effective in caring for the child and coping with the child’s illness. These communicative behaviors can range from how doctors, nurses, and therapists interact with parents or how parents, siblings, and friends interact with the sick child. They can be as simple
as a doctor who sits down in a non-rushed manner to spend time with parents, to parents holding their child while they receive treatment in order to comfort them.

**Pediatric Cancer**

Pediatric cancer is a topic not spoken about often in public. It tends to be a taboo and heartbreaking topic. The mere mention of it in a social situation can dramatically alter the mood of that setting. Although treatment efficacy of pediatric cancer has risen sharply in the past few decades (the cure rate of a child with cancer has gone up 75% from the 20% before the 1960s), it is still the “second-leading cause of death in infancy in developed countries, after accidents” (Friedman & Gillespie, 2011; “Childhood cancer program,” 2012; Garcia Nieto & Day, 2009, p. 358).

**Figure 1:** Leading causes of death among children less than 15 years of age according to the US Mortality Data, 2006, National Center for Health Statistics, Centers for Disease Control and Prevention, 2009
Certain types of cancer are more common in children. Some pediatric cancers are “mainly embryonic in origin and are generally derived from non-ectodermal embryonal tissues” (Friedman & Gillespie, 2011, p. 299). What this means is that children usually develop tumors in “bone marrow, nerve tissue, lymph glands, bone and muscle” in contrast to adults who mainly develop carcinomas in epithelial tissues, for example, “prostate, breast, lung, colo-rectal, uterine and ovary” that “…arise from cells that line cavities or glands” (Simone & Lyons, 1998, p. 3). The most common types of cancers for children are “leukemia, brain and other nervous system tumors, lymphoma, bone sarcoma and soft-tissue sarcoma” (Simone & Lyons, 1998, p. 3).

Roughly 14,000 children and adolescents are diagnosed with cancer every year in the United States. Despite the dramatic improvement in survival rates, pediatric cancer patients endure painful therapies such as chemotherapy, radiation treatments, invasive surgery, bone marrow transplants, and more (Long & Marsland, 2011). These therapies also produce side effects, including “hair loss, weight gain, mood swings, susceptibility to infections, fatigue, and nausea” (Long & Marsland, 2011, p. 57).

Pediatric cancer, and its accompanying side effects, poses great challenges for the caregiving families. Cancer in itself is a very unpredictable disease. One day the child may be feeling well and then severe complications may arise unexpectedly. This sort of unpredictability leads to drastic changes in daily schedules and activity patterns and exacerbates the anxieties for the child and their parents, siblings, friends, and relatives (Pai et al., 2007). Studies of siblings who endure the journey with their cancer-stricken brother or sister suggest that they also experience psychological distress in the form of anxiety, depression, and behavioral problems (Prchal & Landolt, 2009). Other studies have focused on the stress and toll of pediatric cancer on caregiving mothers and on the economic and human cost of having a child with cancer.
Pediatric cancer affects families in multiple ways, including “financial and work issues, health of family, upheaval of family life, and a lost life” (Fletcher, 2010, p. 164).

**Purpose**

Although pediatric cancer afflicts over 14,000 children in the U.S. each year, and affects the lives of countless others, there is not much public understanding about coping with the disease. Cancer is a taboo topic. In the public mind, children are not meant to have cancer. Few in the public know that pediatric cancer patients and their families endure a long road to recovery, one that is fraught with struggles, anxiety, and dilemmas (Long & Marsland, 2011). Further, people commonly mistake the pediatric cancer symbol, gold ribbon, for the yellow one, which honors soldiers fighting a war overseas.

During a personal interview, a mother of a child afflicted with cancer described the experience not just as her son having cancer and surviving it, but as she having cancer and surviving it concurrently. She talked about how she coped with the struggles, the triumphs, and anxieties as a caregiver, taking it as it came. Needed is more research on family members who care for a pediatric cancer patient, including communicative practices they employ to cope effectively with it. The present study delves into this important area of pediatric caregiving through a data-collection method called Photovoice. In Photovoice, respondents take photos in response to a question and add their voice (or narration) to accompany each photo. This study allowed caregivers to narratively express – through photographs – what it means to be going through the journey of their child’s cancer, including identification of communicative strategies that help them in coping effectively.

Over a dozen parents of pediatric cancer patients participated in this qualitative research study, each taking multiple photographs to illustrate their points-of-view. This study is premised
on the notion that a different way of collecting data may benefit parents as they will have an opportunity to capture those communicative behaviors and practices that enable them to properly care for their child, uncovering also the difficulties, dilemmas, and anxieties that parents confront when a cancer diagnosis is rendered. Using photographs and their accompanying narratives to tease out such answers can be very useful for caregivers that follow.

**Photovoice in Participatory Communication Approach**

Increasingly, non-traditional ways of collecting data are being favored by researchers to give voice to those who ordinarily may be overlooked in the research process. Some of these methods have involved simple tools such as pencils, paper, and photographs. These non-traditional, non-textual ways of collecting data serve as a new way of understanding the positions and perceptions of subjects. By opening up alternative ways of gathering information other than text-based surveys, new, richer insights can be discovered that have not been revealed before.

In the present study, parents who cared or were currently caring for a child with cancer, were handed a camera to capture images that illustrated their communicative difficulties and dilemmas when it came to caring for their child and also their communicative practices that allowed them to more effectively care for their child. Using Photovoice allowed the gathering of more than just textual information as is common in survey data or in-depth interviews. Photovoice allowed data to be visually captured in a highly participatory communication process where the participant played a larger role in the data collection. Singhal (2001) stated that Photovoice promotes “dialogue between people, groups and institutions that enables people, both individually and collectively, to realize their full potential and be engaged in their own welfare” (p. 12). Parents of children who have or had cancer took photographs that allowed them to represent their thoughts, and to share, their thoughts visually and orally within the family and
Singhal and Devi (2003) pointed out that participatory communication means “working with and by the people, as opposed to working on or working for the people” (p. 3). Parents were the ones who showcased and narrated their difficulties, dilemmas, communicative behaviors and practices when it came to living with a child with cancer.

Ordinarily “the participatory method of Photovoice” has three overarching goals: …to enable people (1) to record and reflect their personal and community strength and concerns, (2) to promote critical dialogue and knowledge about personal and community issues through group discussions of photographs, and (3) to reach policy makers (Wang, 1999, p. 185).

The present study primarily focused on goals #1 and #2. Through a focus on goals #1 and #2, the results of the present study hold implications for cancer patients, their families, and organizations engaged in cancer treatment and support.

**Examples of Photovoice**

One of the early documented uses of Photovoice was in 1973 when Brazilian educator Paulo Freire and colleagues asked people living in a Lima barrio questions but requested the answers to be in photographs (Singhal & Devi, 2003). The question posed was “What is exploitation?” (Singhal & Devi, 2003, p. 1). A child who had been given a camera took a picture of a nail on a wall. None of this made sense to the adults but the children knew what it was about. The nail signified exploitation to them because they were being charged for leaving their shoe-shine boxes at shops overnight so they would not have to carry them home. The photo and its accompanying rich narrative brought an insight that other community members did not know about, and helped them to take corrective action (Singhal & Devi, 2003).
Numerous other examples of using Photovoice exist around the world. A notable few are described here to illustrate the key components of this data-collection method. Photovoice was employed by Minga Peru, a non-governmental organization (NGO) in the Peruvian Amazon that broadcasts thrice-weekly a half-hour radio show ¡Bienvenida Salud! (Welcome Health) that aims to “both entertain and educate to increase audience members’ knowledge about reproductive health, sexual rights and gender equality” (Singhal & Rattine-Flaherty, 2008, p. 9). Audience members of ¡Bienvenida Salud! were asked to sketch and/or take photographs to reflect on their daily lives. Specifically, children were asked to sketch out their “lived reality” and “Minga Peru’s influence on their community” (Singhal & Rattine-Flaherty, 2008, p. 13). Women were asked to shoot “the reality of Amazonian life, including their perceptions of Minga’s influence on their communities” with cameras (Singhal & Rattine-Flaherty, 2008, p. 13). Children drew schools, homes and churches, but also integrated aspects of what Minga Peru had brought to their communities: fish farms, chicken coops, and agro-forestry (Singhal & Rattine-Flaherty, 2008). Women also allowed their photographs to speak about the influence of Minga Peru on their lives. One woman took pictures of other women crocheting, a skill that was promoted by Minga Peru, so that they could clothe their families and also sell these products to generate income (Singhal & Rattine-Flahety, 2008).

Photovoice was also employed with primary school children from Rothwell and Seacroft, two communities in East Leeds, Yorkshire, England (Burke, 2005). These children were asked to be “researchers of their own play worlds” (Burke, 2008, p. 24). They created a visual diary through the use of pencils, drawing pads and disposable cameras (Burke, 2008). They were asked to take photographs of “places and spaces” for play (Burke, 2005, p. 31). Children took photos of interior and exterior places and spaces. Some children took photographs of school
fields, backyards, public parks, bedrooms, grass, and car interiors because they were “cozy” (Burke, 2005, p. 44). These drawings and photographic journals allowed children a chance to share their experiences in the “limited choices they are able to make every day in where they play” (Burke, 2005, p. 50).

Summary

The purpose of this research project is to use Photovoice to understand the lived realities of parents who are caring for a child with cancer. Parents’ dilemmas, difficulties, and their communicative behaviors and practices that lead them to cope are documented. This study allows the participants to be fully engaged in the data collection process. Taking photographs and then orally narrating them gives the participants the opportunity to say their bit as opposed to having those interpretations made for them.

The next chapter reviews literature on pediatric cancer care, focusing on those who are especially affected by it. Chapter 3 describes the methodology used for this research study. Chapter 4 showcases the results and findings of the present study and Chapter 5 presents conclusions of the study and its implications.
This chapter reviews the literature on the role of communication in healthcare contexts, including its importance for parents and siblings in coping with pediatric cancer. A background on Photovoice as a participatory communication method of research is provided, and research questions to guide the study are presented.

**Role of Communication in Health and Healing**

Whether it is pediatric cancer, another ailment, or another crisis, communication plays a critical role in caregiving and healing. The field of health communication “has developed into a distinct genre” (Bauer & Orbe, 2001, p. 142). There exists a vast literature on how parents, children, doctors and staff communicate about the disease in the context of health and healing.

Anderson and Kaye (2009) reviewed how doctors, nurses, and staff communicate effectively with their patients as well as their family members. They discussed the importance of “therapeutic alliance” in which health-care providers respond “to patients’ uncertainties, fears, and particular life circumstances with efficiently organizing care” (Anderson & Kaye, 2009, p. 775). This therapeutic alliance manifested itself as communicative practices to effectively engage with the patients. One manifestation, for instance, was the “one-page summaries” which allowed doctors and nurses to know what was going on with their patients beyond the medical charts and records (Anderson & Kaye, 2009, p. 776). Another practice they engaged in was “editable calendars” (Anderson & Kaye, 2009, p. 776). As cited by Anderson and Kaye (2009), Anderson and Salazar-Abshire (2006) showed that these calendars “scheduled therapy, including chemotherapy, surgery, radiation treatments and count checks as organized around the important
events in patients’ lives (e.g., birthdays, graduations, family weddings, holidays)” (p. 776). This act alone signified to the patients that cancer was just “one aspect of their lives” (Anderson & Kaye, 2009, p. 777).

In the health care context, communication practices become even more important when it comes to conveying, for instance, an end-of-life diagnosis, or breaking the news of a loved one’s passing away. Cluck and Cline (1986) stated that “traditional coping ‘tools’” such as relying on family, friends, and therapists may be missing because of “the splintering of the extended family and the geographic and social mobility characters of America’s changing social structure” (pp. 308-309). In such situations, grieving persons found solace through engagement in social support mechanisms, self-help groups, and the like. Cited by Cluck and Cline (1986), scholar Naisbitt (1982) argued that self-help groups helped the person “reclaim ‘personal control over the mysteries of life and death’” (p. 312). These self-help groups allowed for grievers to create “empathic understanding” so it “facilitates empathetic honesty” (Cluck & Cline, 1986, p. 313). These advantages of self-help also led members to establish a “lack of hierarchal structure” (Cluck & Cline, 1986, p. 313). This meant that while other forms of support groups, such as “professional psychotherapy groups,” worked by having communication from “subordinate to superior,” self-help communication leveled the hierarchies (Cluck & Cline, 1986, p. 313).

The role of communication practices in alleviating anxieties become increasingly important with rising severity of the medical situation. Let us consider, for instance, a situation involving an organ transplant. Stressors included not just going through the process of receiving an implant, but also the process of waiting for a donor to come through (Bauer & Orbe, 2001). As cited by Bauer and Orbe (2001), Cohen and Wills (1985) stated how social support for a person dealing with an organ transplant “acts like a buffer” (p. 142). These authors cited Coyne
et al. (1990) to emphasize that close familial and friendship relationships were the most significant sources of social support. Such is not exclusive to organ transplant patients but to other medical crisis as well.

Several networks exist in the real and virtual world to provide social support for patients and their families. The NCTSN (The National Child Traumatic Stress Network), for instance, aids caregivers through publications such as *At the Hospital: Helping My Child Cope What Parents Can Do*. Such resources, and others like them, offers guidelines to parents and caregivers to more effectively cope with a loved one’s illness, and to make the hospital experience a less traumatic one (Medical Traumatic Stress, 2004). The website, Children’s Hospital of Philadelphia, offers insightful suggestions on how parents and caregivers can effectively cope during medical procedures and interventions (Medical Traumatic Stress, 2004). The site offers helpful tips on how to talk to the child, how to get them to relax through breathing exercises and/or fun activities like blowing bubbles or playing a harmonica (“Coping during healthcare”).

**Coping, Caregiving, and Pediatric Cancer**

Studies on coping with pediatric cancer have emerged over the years and several of them have focused on posttraumatic stress disorder (PTSD), the “transition from pediatric to adult care,” and ethical issues regarding the involvement of pediatric cancer patients in drug development trials (Greenfield, Absolom, Davies, Ross & Eiser, 2004, p. 83; Aleksa & Koren, 2002).

Butler, Rizzi and Handwerger (1996) studied if pediatric cancer patients and survivors suffered from PTSD. While PTSD was reported in children going through cancer and those who survived it, Greenfield et al. (2004) argued that more should be done to alleviate the transition
between pediatric care and adult care. The authors argued that the transitional shift from pediatric to adult care can be “intimidating to the young patient who is unaccustomed to individual consultancies” (Green et al., 2004, p. 85). Green et al. (2004) argued that pediatrics offers a more “holistic approach” with a natural emphasis on family engagement and involvement as opposed to adult care where the emphasis lies in the patient taking control over his or her health (p. 85). Aleksa and Koren (2002) argued that children need to be involved in the development of cancer drug therapies so that their voices, concerns and body types, are factored into the process:

In addition to growth in physical size, dramatic changes in body composition, body proportion, physiology, neurological maturation, and psychosocial changes take place from infancy to childhood; thus, all of these changes taken together will determine how a child responds to disease and in turn, to therapeutic modalities. Therefore, not only are children different from adults but they also differ from one another in their maturation. (p. 260).

The authors concluded that while involving pediatric cancer patients may seem unethical in drug trials, there is a need for children’s voices to be heard. Children need to be an integral part of the drug trial loop of modern medicine. The following sections focus on studies done regarding mothers, fathers and siblings of cancer-stricken children and their experiences with pediatric cancer.

**Family Caregiving in Pediatric Cancer**

Just like there are studies that focus on children undergoing the trials and tribulations of being afflicted with cancer, various studies have focused on caregivers and family members: mother, father, and siblings. Some studies have also focused on the relationship between the
mother and father, especially the stress that comes with, and continues with, a pediatric cancer patient’s diagnosis and ensuing treatment.

Hoekstra-Weebers, Jaspers, Kamps, and Klip (1998) conducted a study on marital problems once the news of a child with cancer is broken. The study offered insights about how a partner’s coping style influenced marital satisfaction (Hoekstra-Weebers et al., 1998). Common stressors included side effects experienced by the patient, insecurity and anxieties about their survival, and coping with constant hospitalizations (Hoekstra-Weebers et al., 1998). While some couples grew closer because of their child’s illness, others drifted apart (Hoekstra-Weebers et al., 1998).

Lannen et al. (2010) conducted a study on how parents come to grips with a diagnosis of their child’s incurable cancer. The authors found that how, when, and from whom the information is received makes a big difference for parents in terms of how they coped. The parents’ ability to take in the news about their child’s illness was mediated by three variables:

Parents with no history of depression, those who reported that they shared their problems with others during their child’s illness, and those who thought the information was given in an appropriate manner were more likely to have absorbed the information given (Lannen et al., 2010, p. 261).

Lannen et al. (2010) examined the way parents reacted in these tough situations. Things that might seem inconsequential made the biggest difference in the lives of these parents and their abilities to cope with the difficult situation. The role of communication and specifically the provision of necessary and timely information about the diagnosis and treatment options were the key determinants of how well they coped (Lannen et al., 2010).
It is useful to highlight that parents of a pediatric cancer patient are not only involved in taking care of the child’s illness, but also trying to raise, to the extent possible, a “normal” child. Jithoo (2010) discussed the differential impact of open and protective approaches in conveying a cancer diagnosis. The foundation of the protective approach, popular some decades earlier, consisted in that “communication about the disease and illness was the sole domain of the physician, who decided whether and to whom to reveal the diagnosis” (Jithoo, 2010, p. 351).

In the past few decades, more open approaches have found currency: i.e., parents as well as the pediatric cancer patient have to be informed openly about what is going on. Full disclosure is valued. While processing a cancer diagnosis “communicative factors that seemed to make a difference for parents included information seeking and information avoidance behaviors; satisfaction with the communication encounter and availability of support structures” (Jithoo, 2010, p. 354). It was not uncommon for the parents to drown in technical medical jargon, struggle with decisions about treatment, and confront fears and anxiety about the prognosis (Jithoo, 2010). To cope, most parents “found it easier to regurgitate” information provided to them (Jithoo, 2010, p. 355). These parents and their children, over time, became knowledgeable about the situation in a very factual way: they knew medical terms that aided them in the description of routines, procedures, modalities in diagnosis and treatment. Most parents, however, chose not to tell their child the severity of their condition. Others waited for the child to start the conversation before responding, and some disclosed very little. However, over time, children picked up a good deal of information from other sources around them (Jithoo, 2010).

The effect of pediatric cancer on siblings has also been studied. Breyer, Kunin, Kalish and Farkas-Patenaude (1993) noted that siblings, initially, tended to follow what goes on with
their ill brother or sister from the sidelines. They knew something was wrong; yet, there was little they could do. The disruption in an established sibling relationship became apparent when parents focused more on the ill child, giving them the attention they needed and often without realizing that the sibling may have felt neglected (Breyer et al., 1993). In a study, Breyer et al. (1993) reported that 44 percent of siblings noted being “sad or unhappy on learning of their sibling’s diagnosis” (p. 204). Healthy siblings described being actively involved with the ill sibling. They reported “playing with the ill sibling or visiting him/her in the hospital,” noting that such actions helped them in dealing with the situation (Breyer et al., 1993, p. 204).

Other studies like the one conducted by Barrera, Fleming and Khan (2004) found age and gender to be “modifying factors” in the psychological adjustment of siblings to a cancer diagnosis of a brother or sister (p. 103). The authors concluded that adolescent females were more likely than adolescent males to experience depression due to their sibling’s illness (Barrera et. al., 2004). Siblings with more family support accounted for less behavior problems than those with lesser support (Barrera et al., 2004). Also, in general, female siblings were prone to more anxiety and behavioral problems than males.

Houtzager, Grootenhuis, Hoekstra-Weebers and Last (2005) looked at the quality of life (QoL) issues for siblings of pediatric cancer patients. It was reported that “there is a considerable subgroup of siblings who reported difficulties in a number of areas” depending on their age like “cognitive” and “emotional problems” for 7-11 year olds and 12-18 year olds and “motor difficulties” for 7-11 year olds (Houtzager et al., 2005, p. 83). Few participants expressed positive emotions. Gender was also examined in this study. Adolescent female siblings were more likely to present problems regarding their social interactions outside the home and “indicating that they are less satisfied with relationships with family members, peers,
and others” (Houtzager et al., 2005, p. 81). Yet, even with all the negativity, there were some positive notings. With siblings who displayed positive expectations, their adjustment to their sibling’s illness was better. Predictive control, as Grootenhuis and Last (2001) pointed out, was responsible for lower incidence of anxiety and depressive symptoms in those children whose brother or sister was going through cancer.

**Photovoice in Participatory Communication**

The idea of using Photovoice, as stated previously, was introduced by Paulo Freire and his colleagues in the early 1970s. They invited photographs and accompanying narrations from participants in a Peruvian barrio in trying to understand the many faces of exploitation. In the past four decades, numerous research studies in areas like health, education, and community development have used Photovoice as a data-collection method, giving the means of producing knowledge to the primary respondents based on “their personal views of reality” (Singhal & Devi, 2003, p. 4). To illustrate, some studies using Photovoice in different areas are reviewed here.

**Photovoice in Health**

Wang (1999) described Photovoice as a participatory action research that can offer very distinct insights into women’s health. Wang (1999) stated that some of the key concepts of Photovoice include “images teach; pictures can influence policy; and Photovoice emphasizes individual and community action” (pp. 186-187). She claimed that literature reviews, surveys, and statistical studies can only provide so much information and not enough depth to what women are really going through such as reproductive health, inequality between male and female health status, menstrual cycles, etc. Another similar study done by Hergenrather, Rhodes,
Cowan, Bardhoshi, and Pula (2009) used Photovoice to understand community health issues and disability priorities.

Necheles et al. (2007) also integrated Photovoice to promote health. Students were given cameras to capture images of healthy lifestyles and those factors which influence it (Necheles et al., 2007). The health sector has also used Photovoice to not only understand the experts’ point-of-view, but also those in the community who also have something of value to say.

**Photovoice in Education**

One of the studies in the realm of education that involved Photovoice was conducted by Luttrell (2010), which focused on working-class immigrant children in U.S. public schools. Titled “‘A camera is a big responsibility’: a lens for analyzing children’s visual voices,” Luttrell (2010) recognized the work of other Photovoice scholars such as Wang and Burris (1997); Wang (1999); Strack, Magilla and McDonagh (2004) who “put cameras in the hands of people who have been left out of policy decision-making or denied access to and participation in matters that concern their daily lives” (p. 226). Another scholar, Ryan (2009), gave young people cameras in order to capture, through their eyes, their actions to make their school more inclusive especially for students with special needs. These students photographed places within their schools where they felt included and excluded. Interestingly, even though their schools preached inclusion for all, students with disabilities still found exclusion in many not so obvious places.

Burke (2007) also used Photovoice to better understand “pupil participation in the design of learning environments for the future” (p. 359). She claimed that even though these classrooms and spaces for learning are aimed for the child’s use, their consideration and perceptions have been silenced for far too long. Further, Iarskaia-Smirnova and Romanov (2009) argued that teaching can be enhanced through use of visuals as it can lead to the
“understanding of representations as cultural texts, to develop interpretations of meanings in the socio-cultural context and to decode images of social relations and individual experience” (p. 61).

Photovoice has also been used as an aid to children with autism and proved helpful for their teachers. Carnahan (2006) discovered that barriers to participation of autistic students could be removed through structured membership activities involving photographs. Photographs allowed for both autistic children and their teachers to be engaged in “nontext-based materials” in which children did not feel that they were excluded or left behind (Carnahan, 2006, p. 48).

**Photovoice in Community Development**

Wang, Morrel-Samuels, Huchison, Bell and Pestronk (2004) used participatory action approach to gather information regarding “community assets and concerns, [to] critically discuss the resulting images and communicate to policymakers” (p. 911). Wang, Cash, and Powers (2000) also applied the technique of Photovoice to study homelessness. Homeless men and women were asked to take photos to raise awareness of their living conditions, highlighting areas for improvement.

In sum, Photovoice is a participatory-based research approach that hands the power to those who know a great deal about what is being researched. This approach allows working with and not working on participants (Singhal & Devi, 2003). Once photos are taken and their accompanying narrations provided, insights emerge which may not have been possible before. Photovoice can help uncover new issues that survey research or expert-driven research may overlook. It gives voice in new ways allowing people an opportunity to explain their situation pictorially and orally.
Research Questions

Drawing upon the above literature review on the role of communication in healthcare contexts, including coping effectively with pediatric cancer, and on the conceptual sensibilities associated with Photovoice, the following broad research questions guide this research.

RQ1: How do family members record and talk about their experiences with pediatric cancer?

RQ2: What are some communicative difficulties and dilemmas that family members confront on a regular basis when caring for a child diagnosed with cancer?

RQ3: What are some communicative behaviors and practices that family members engage in to effectively care for a child diagnosed with cancer?

RQ4: What are some communicative behaviors and practices that aid family members in emotionally dealing with the child’s cancer?

For a difficult topic like pediatric cancer, Photovoice can help break the ice between the participants and researcher, allowing for the building of trust between them. The photographic representations and their accompanying narrations allow participants to express themselves in deep and rich ways.

In the following chapter, the methodology and data-collection procedures employed to answer the research questions are detailed.
Chapter 3

Methodology

In the present chapter the methodology and data-collection processes employed in the present study are described. It may be useful to mention upfront that the present researcher has undergone IRB training and an IRB application was filed to implement this research. Upon receiving approval from IRB, consent forms were distributed both in English and Spanish to the participants and signed before any data was collected.

Site of Research

The primary site for implementing this research was Candlelighters of El Paso. Candlelighters is a support organization for children and their families who are currently afflicted or affected by pediatric cancer. These include children and families who have just been diagnosed, those in remission, those who have relapsed, those in treatment, survivors, and those who have passed away (Candlelighters of El, 2010).

A meeting with Ms. Beate Burdett, Director of Development at Candlelighters of El Paso, took place while working on the production of a video for the Candlelighters’ annual Walk of Hope in El Paso in mid-Fall, 2011. This production experience inspired the present study. By serving as the cameraperson and interviewer of parents who take care of cancer-stricken children, the idea of carrying out this research at Candlelighters became more concrete. While interviewing family members of pediatric cancer patients, it was apparent that the parents felt deep gratitude toward Candlelighters. They found it to be a comfortable, safe, and supportive space.
Principally, the present research was carried out keeping in mind the convenience of the parents. Locations varied. Local restaurants, a local pedi-oncology clinic in one West side based hospital, and the Candlelighters facility served as meeting spots for the participants of the study and I. Accommodating to the needs of the participants was always a top priority.

**Participants**

The 12 research participants were parents of children undergoing cancer treatment (for any type of cancer) and those who had gone through treatment in the past. Children ranged from a few years to up to 21 years of age since Candlelighters helps children from ages 0-21 (Candlelighters of El, 2010). The parents’ current marital status, ethnicity, place of residence, their socio-economic status, and age were not determining factors in interviewing them. Candlelighters helped facilitate the participation of parents in the present study with me making contact via telephone. They were told their real names and those of family members they mentioned would not be used for this study. Instead code names were employed.

During the first meeting with potential respondents, I presented an overview of the study and outlined what it would entail the participants to do. The floor was opened up for questions and clarifications were provided. Consent forms were then distributed. Once the consent forms, both in English and Spanish, were signed, cameras were distributed to the first group of four participants, including one married couple (a man and a woman) and two mothers. Directions about what to do next were provided. More participants were recruited over the next several weeks. In total, there were 12 participants, 10 female and two male, who participated in the study. Each participant was told that they could opt out of the study at any time. None did so. They were also given my contact information in case they had any questions or concerns.
Participatory Photovoice

The method used for this study was Photovoice. As noted previously, several studies using Photovoice have been undertaken. Singhal and Durá (2009) used a modification of Photovoice to encourage respondents to sketch instead of taking photos. Sketching is inexpensive and elicits a more active participation from the respondents who begin with a blank canvas. In the study of the effects of Minga Peru’s popular radio program, ¡Bienvenida Salud!, some of the participants sketched while others took photographs. Figure 2 provides an example of one such photograph taken by the participants involved in the study conducted by Singhal and Rattine-Flaherty (2008) in the Amazon. It is included here to illustrate the basic premise and principle of Photovoice.

Figure 2: Adela (center) talking to the women about family violence in their community.

Singhal and Rattine-Flaherty (2008) noted that this picture not only had an accompanying narration, but pointed to
the strategic choice of location to discuss family violence. Men are absent when women are washing dishes by the river bank, so this location represents a ‘safe’ environment for women to talk freely. The photo also shows the advantages of a having a community *promotora* from within the community. Her local presence means she is always on duty, improvising as needed, and capitalizing on opportunities when they come along to make her move. This photo also shows the complexity of social change processes: women find ways to collectively discuss oppressive social norms, aided by a peer change agent, but do so in the safety of ‘their’ space, and within the confines of their traditional roles (pp. 18-19).

From photographs and narrations such as the one provided by Adela, it becomes possible to gather “richer and deeper explanations often wrought with emotion” (Singhal and Durá, 2009, p. 25).

**Participant Observation**

There was also some participant observation involved in this research. Lindolf and Taylor (2002) described the “validity of participant observation [as] deriv[ing] from the researchers’ having been there” (p. 135). As a researcher, I visited some pediatric cancer care facilities and observed interactions between patients, their families, and their caregivers. These observations allowed for a better contextual understanding of the photos and their accompanying narrations.

**Instructions and Narrations**

Once the consent form was signed, each responding parent was given a disposable camera (the married couple shared one camera) and was provided instructions on how to use it. All respondents rehearsed taking at least two photos so they were clear on how to handle the
disposable camera. Once the respondents took the photos, the cameras were collected; the films were developed, and then returned back to the respondents. Of the roughly two dozen photos, respondents were asked to select six to eight photographs, which they believed to be the most “telling” and “meaningful” for the stated purpose, and narrate them. This took the form of an interview, but it was the participants who took control of the interview. They were invited to share what the photograph meant to them and why they chose to take it. Learning took place along with the participants about what it is like to be a caregiver of a pediatric cancer patient. As the narrations progressed, the difficulties and dilemmas faced by the parents in caring for an ill child became clearer. Numerous examples of communicative acts and practices that helped them cope effectively with their child’s illness surfaced through these photographs and their narrations.

It is important to mention here that some parents brought photos from their previous albums to supplement the Photovoice photos they took. Some of them are included in Chapter 4 for a richer and more nuanced understanding of their coping behaviors.

A Word on Relationship Development

Engaging in several activities over several months smoothened the process leading up to the implementation of the present research, building relationships, and having numerous informal conversations. The video production experience with Candlelighters in Fall, 2011, allowed the interviewing of people engaged in pediatric cancer care: the mother of a child who had been diagnosed with cancer at a very young age; an oncologist; Candlelighters Director of Development, Ms. Beate Burdett; two sisters, one of which had been diagnosed with osteosarcoma at the age of 11; a young man also with osteosarcoma; and a young girl who had
suffered through leukemia. These interviews were very useful in establishing a context for
understanding how parents and caregivers cope with pediatric cancer.

Several visits with Candlelighters of El Paso before the research got underway helped me
understand the day to day events that family members have to go through in order to care for
their loved ones. I was invited to, and participated in, several events hosted by Candlelighters,
which included the children and their parents. It offered an opportunity to understand how
pediatric cancer affects caregivers. One notable event was the Valentine’s Day Dance in which
the children and their parents gathered to celebrate life and love. They also crowned a child king
or queen as a reward for raising money for the cause of pediatric cancer. The event was marked
by smiles and laughter, giving a peek into the solidarity aspects of coping with cancer. Other
events included hospital visits to see the process a child goes through when preparing to receive
treatment. Interaction between child and medical staff, parent and medical staff, child and
parent, child and child, and parent and parent were observed. I also took part in a couple of
group support meetings and some volunteer events organized by Candlelighters.

Participating in these events allowed me to delve deeper into the lives of these
courageous families, build relationships, and in providing a context for making sense of the
photos and their narrations. Participating in these information-seeking activities helped alleviate
the questions, concerns, and some insecurity I had and allowed for further building of trust with
the respondents. In the next chapter, the findings of this research study are presented.
In this chapter, an analysis of the photographic data and their accompanying narrations provided by the parents of children with pediatric cancer or those who had gone through pediatric cancer is presented to answer the research questions posed in Chapter 2.

Before answering the research questions, a small note about the Photovoice process is discussed. Photovoice allowed parents to not just recall why a certain photo was significant to them from a coping perspective, but also triggered memories of other events associated with the current health status of their child. Some children were still in treatment; some were almost out, and some had been out for a while. No matter what stage of treatment the children were in, the sentiments expressed by parents were fairly common.

**Recording Experience and Talking About Them**

RQ1 asked: How do family members record and talk about their experiences with pediatric cancer?

Some parents emphasized that taking pictures was a crucial way of recording their experience as well as their child’s ordeal through cancer. Yet, not all the parents thought of doing so while their child was undergoing treatment. One mother, Participant J, noted:
Other moms, however, pointed out that this experience needed to be recorded so their children knew what they had gone through. One mom, Participant M, whose son is only four years old, said: “...I take pictures of him so I can show him when he starts growing up what he was doing and making and going through” (February 28, 2012). Another mom had a similar answer: “When you’re going through treatment that’s when you take the most pictures, [I] took pictures of almost every moment, now not so much” (Participant P, February 6, 2012).

Participant P added that she took photographs during her child’s illness because she never knew what would happen the following day: “We had good days and then the next day was a bad day…I mean it just changes drastically” (February 6, 2012).

All but one participant took pictures of their children while in treatment. Other participants who took photographs of their children mirrored the responses listed above. One of them, Participant I, said she had always been one to take pictures, even before her son was diagnosed. That was just something she enjoyed to do and once her son was diagnosed it was only natural for her to document the journey though photographs. She noted that she brought those pictures, old and new, to the hospital:
Yo siempre he sido muy detallista. Cuando estaba internado yo le ponía fotos en la puerta de su cuarto de cuando estaba jugando beis y unas de bebé.

I’ve always been very detailed about things. When my son was in the hospital I would put pictures on the door of his room of when he played baseball and some of when he was a baby.

( Participant I, February 22, 2012)

While most parents felt a need to record the family ordeal, they communicated their feelings with different levels of emotional intensity. Some reached deep within them and cried during their narrations; others were more straightforward and more matter-of-fact in expressing themselves. Such parents seemed to treat pediatric cancer as something that happened in their life and hence was supposed to be dealt with in stride, depending on the situation at hand. One of the male participants in the study, Participant G, emphasized:

I know it’s hard but I know it’s pretty self-explanatory what you have to do with a family member like that. You have to learn. I think you get tied up dealing with the stuff you have to do to take care of him and it kind of takes your mind away from having to deal with the actual cancer or whatever problem you have. I think it takes that away just you knowing you have to make sure his hands are clean, make sure the house is free of dust…anything that can get him sick, you know. I think that helps take a lot of the bad feelings away…I think that it just takes your mind off of it (February 27, 2012).

An argument can be made that the above response seems to be a gendered one; however, another participant, a mom, also communicated that she purposely compartmentalized her hospital and home life as a way of coping:
Definitely because it’s so stressful here and when you’re here you don’t have a life… it’s kind of depressing because you think about ‘Oh I want to go home and be with the family, with my daughter, cooking home-cooked meals for him that he loves and that my family loves,’ but I can’t and it’s kind of been hard so whenever we’re here it’s like a job. Whenever you go into your job you clock in and then once you leave you clock out and you don’t even want to mention whatever you’ve gone through at work or if it’s been stressful because you want to relax and just enjoy the time that you have at home with your family… totally apart, both things (Participant M, February 28, 2012).

Most parents, as noted previously, expressed more feelings and emotions about the topic. Many went into more detail about their day-to-day activities and what they did to effectively cope with their present situation. Participant P2 and Participant L were particularly emotional. Participant P2 was the only parent in our study whose child had passed away and she communicated her experience with both tears and smiles. She remembered good days fondly and in great detail. Now given her son had passed, she looked to her eldest daughter, granddaughter, and her younger children for support:

_Por ejemplo, aquí Lorenzo… esa pijama era de él (hijo que falleció), esas pantuflas. Yo dije no sé las va querer poner y se las pone y has de cuenta que es que yo lo veo así de aquí para abajo y digo es Alán aunque se que no es pero el por amor lo hace de ponerse sus cosas._

For example, here Lorenzo… those are my son’s (son who passed away) pajamas, his slippers. I said to myself, he’s (Lorenzo) not going to want to wear them but he does and it’s like from here down it’s like I’m looking at Alan, but I know he’s not, but he (Lorenzo) does it out of love for his brother.

(Participant P2, February 24, 2012)
In sum, this research question allowed a better understanding of how parents recorded their experience with pediatric cancer and how they talked about it. Most participants felt comfortable enough to share their thoughts, memories, and emotions openly. Some parents coped by taking things, purposely, in their stride, while some others allowed themselves to be in the moment with their struggles, fears, and anxieties. This first research question paved way to dig deeper. The next section details the specific difficulties and dilemmas that caregiving parents faced, and ways they coped with their struggles.

**Communicative Difficulties and Dilemmas**

RQ2 asked: What are some communicative difficulties and dilemmas that family members confront on a regular basis when caring for a child diagnosed with cancer?

Going through cancer treatment is a difficult ordeal for young children and their families. Parents do not usually expect their child to be receiving chemotherapy, radiation, and/or invasive surgery to remove a tumor. If one does not personally know of a child going through cancer treatment, it is not something that is high on the agenda of public discourse or a topic of daily conversations. As a result, children and their families who go through cancer face many communicative difficulties and dilemmas. Some of the common difficulties faced, based on the responses received, include other people’s ignorance on the subject matter, limited or insufficient spousal support during the family ordeal, and caregiving concerns for not just the ill child but also their siblings. These are coupled with all the fears and anxieties associated with treatment outcomes, financial burden, and relational responsibilities.

**Public Ignorance**

Several mothers emphasized that there is too much public ignorance about pediatric cancer. This meant they not only have to worry about their child’s wellbeing at home and at the
hospital, but out in the public as well. These difficulties and dilemmas were, interestingly, not photographed as some of the respondents purposely opted to focus on more positive aspects of caregiving, and also because they did not have the opportunity to photograph the difficult moments in public when they happened. Yet, during their narrations of pictures that involved positive aspects of caregiving, several narratives were about the difficulties and dilemmas they faced because some of the photographs triggered those memories. Participant P noted:

I wish I would have taken a picture of one day when we were at the store…and there was this mom behind me and I had Jerry in the cart and he had an NG tube (nasogastric tube) in his nose and when I took off his mask…she looked at him and took her kids away from Jerry…that got me so mad and I turned around and I looked at her and I told her ‘You know what, he has cancer and it’s not contagious,’ and I kissed him on his forehead. She just looked at me and walked away. …I wish I could’ve taken a picture of that moment because it’s going to stick to my mind forever how people are so ignorant…I rather them ask what’s wrong with him than to do that cause they hurt us without even knowing (February 6, 2012).

Participant P was not the only one who spoke about public ignorance about pediatric cancer, inadvertent as it may be, and what that means for caregivers and the afflicted child. Other moms touched on the subject of how they have seen others suffer from public ignorance and how they have experienced it firsthand. Participant D narrated a similar experience:
Me toco nada más un ves toparme con una familia que sus niñas le preguntaron a su mamá que por qué mi niña traía la boca cubierta y la señora les dijo ‘es que ella está enferma y te puede contaminar…lo que ella traé te lo puede pasar por eso la están cuidando.’

(February 13, 2012)

Participant I emphasized the need to educate the public so that such incidents are not hurtful, especially because they are not driven by malice.

Que aprendan que es parte de ellos porque mucha gente lo ve como algo contagioso como que algo a mí no me va pasar. Cuando ven a los niños sin cabello…las miradas y todo eso porque no estamos educados para eso.

(February 22, 2012)

Parents also talked about such difficulties in their child’s school. Participant L recalled how her daughter would be teased at school because of the loss of her hair. One classmate kept harassing her, “you’re bald, why are you wearing that ugly stuff on your head, why do you look like that?” (Participant L, February 9, 2012). The harassment continued and finally Participant L decided to intervene:
I went straight to her and said ‘Mija, can I talk to you? You know Ellen is sick; she’s going through chemotherapy that’s why she doesn’t have any hair. She’s not contagious and you should not be rude to her.’ She started stuttering and then she said ‘I didn’t say anything.’ ‘Mija, I know you do,’ and then Ellen started crying and the little girl was like ‘Oh I didn’t know.’ That’s when I told Ellen, when we went home, ‘You know Mija what happens is that people or parents don’t tell their kids’ (February 9, 2012).

Other parents also emphasized the need for greater public awareness about pediatric cancer. Parents noted that the primary vehicle of public awareness about pediatric cancer comes from the commercials for St. Jude’s Hospital. Participant P noted that enhanced public awareness would help people overcome their fears about pediatric cancer, necessarily, being a death sentence in each case (February 26, 2012).

What can be concluded about manifestations of such public ignorance, even if inadvertent, is that parents going through pediatric cancer have not been able to effectively find a way to cope with, or deal with, such situations. Personal feelings are hurt when there is lack of public compassion for the ones who suffer. While parents react instinctively in the moment and do so in their capacity as caregivers, protectors, and child advocates, they wished for greater compassion. So while it is important to focus on how caregiving parents cope with the lack of public knowledge on this issue, it also behooves us to figure how the public could be better prepared for such scenarios.

**Limited or Insufficient Spousal Communication**

In addition to dealing with treatment regimens, hospitalizations, public stares and teasing, some of the parents talked about the difficulties arising because of limited spousal communication or because of insufficient spousal support. The responsibility of caring for the ill
child fell mostly on mothers, who made up a majority of the respondents. Some of the women participants noted that they wanted to communicate to their spouses what they were feeling about the situation, but either could not do it, or did it in a manner that they found to be satisfactory. One of the participants, Participant M, justified it by saying that is just the way her and her husband do things; they do not talk about it and when the subject is brought up, it is only for as long as it needs to be talked about (February 28, 2012). Limited spousal communication “worked” for this participant or rather she made it work for her, but for most mothers such was not the case. They looked for richer communication with their husbands during this family ordeal.

Participant D noted:

**Yo no tuve ayuda de mi esposo. Por ejemplo**

I didn’t receive help from my husband. For example, my husband, like all men, is

**porque mi esposo, como todos los hombres, son muy débiles...no pueden ver a su hija**

weak…they can’t see their daughter crying

**llorando porque se desasen...entonces yo pase por todo el proceso y no tuve oportunidad de llorar pero sin embargo yo no le di a mi hija esa debilidad.**

because they fall apart…so I went through the whole process and I didn’t have an opportunity to cry, but still, I didn’t give my daughter that weakness.

(February 13, 2012)

While it may not seem as such, the situation Participant D described about limited spousal support, actually enabled her to give her daughter the strength she needed to keep going. Mother and daughter passed that strength among themselves to make each other stronger in spite of the father’s absence. Another participant. Participant M2, also expressed a similar sentiment:
We really don’t talk about Julia being sick...I mean we talked, but we didn’t talk about it. He kind of just didn’t want to. He just wanted to like ‘okay we already know, we need to do this, this let’s move on’ and that’s kind of how I did it too, you know. I didn’t talk...I didn’t even cry. So a lot of parents cried but I didn’t. Like tears came out when the doctor told me what was wrong with her but like for me to cry, I didn’t (February 29, 2012).

Again, this quote shows how this mother opted not to talk because she did not feel she had that space to do so with her husband. She decided her best bet was to keep her emotions to herself. This was her way of coping with the situation even though most people would consider it a non-coping strategy. There is a noticeable similarity between the two responses provided above by the two caregiving mothers. To deal with the limited bandwidth that they shared with their spouse, they focused on the wellbeing of their child, both gaining and giving strength in the process.

Interestingly, the photographs that stirred the narrations discussed above were about something else. However, as parents would speak about one picture it would trigger an abundance of memories, including frustrations and anxieties. Those evoked memories had a generative effect in terms of leading to richer, nuanced, and deeper conversations.

**Caregiver for Other Children TOO**

Only one mother had a single child, the one who had cancer. The rest of the participants had other children besides the child with cancer. Their worries and concerns went beyond the ill child and were expressed in terms of not being able to be there for the others. The ill child demanded almost 100% of their time, and their other children suffered because of it. Participant M2 still to this present day bemoans not being able to be there for her middle child as much as
she wanted to. However, to help her middle child not be completely at a loss as a result of her pre-occupation, she got him involved in activities she knew he would enjoy.

Middle Child and Karate Instructors Enjoy Time Together (*permission granted by participant to use photo*)

She involved her middle child, for instance, in karate and has seen how that has helped her child flourish and adapt a bit better to the situation at hand:

So for him to have other adults, role models, to look up to was important to me as a parent and then for his self-esteem...it improved. He was able to get attention from another source cause I felt like I wasn’t there for him (Participant M2, February 29, 2012).

Other parents had similar experiences with their other children. Most siblings, especially older ones, knew that this was the way it was supposed to be but they were, no doubt, affected by their parent’s absence. Often parents had to stay at hospitals for months, which meant they could not
see their other children as often as they would have liked. Another participant, whose daughter fell behind in school because of an ill sibling, is now working extra hard to get his youngest daughter back on track.

Child and Younger Sister Play Together (*permission granted by participant to use photo*)

In narrating the above photograph, in which both sisters are playing, the father noted:

We had a lot of problems with her little sister Betty. During those three months that we were in the hospital we didn’t take care of her like a parent does and she fell behind in school and we blame ourselves, but it’s something we had to cope with, you don’t try to put any children in front of…we don’t pick one out, but this was our priority. To this day we feel bad because she still hasn’t caught up; we’re still struggling with her. She’s been seeing a therapist and everything’s been good. We put everything in the hands of God (Participant J2, February 6, 2012).
There was more to simple self-blame. Both father and mother offered to give their youngest child any help she needed to make up for the time they were not able to be with her. It was another way of coping with guilt about lost time.

While some parents were making up for lost time, one parent, Participant J, talked about the jealousy that surfaced between her two sons.

*Yo tuve muchos problemas con mi hijo* I had a lot of problems with my son because

*porque él como que tenía muchos celos de* he was jealous of his brother (ill child).

*su hermano. Empezó a ponerse celoso* There was a moment where I just wasn’t

*porque yo tuve que dejarlos en la casa* home because I had to take care of my son

*solos. Llegó el momento en que ya no* and he started yelling at me saying that he

*estaba, tenía que estar cuidando al niño y* wished he was the one who had cancer so I

*mi hijo, él me gritaba que porque mejor él* could stay with him.

*no tenía el cáncer para que yo me estuviera* (February 28, 2012)

*con él.*

In sum, pediatric cancer does not only require parents to cope with what is happening with the sick child but also dealing with aspects of public ignorance, with spouses who may have different styles of communicating, relating, and responding (or not) to the family ordeal, and with aspects of guilt and jealousy involving parenting and sibling care.

**Communicative Behaviors and Practices for Effective Care**

RQ3 asked: What are some communicative behaviors and practices that family members engage in to effectively care for a child with cancer?

Pediatric cancer parents have an enormous amount of responsibility on their shoulders. The responsibility falls on them to take their child to the doctor, watch what they eat, look out for
new symptoms, pathologies, and the like. Even though other parents did not say it in as straightforward a manner as Participant I, they all emphasized that “if their child was okay, then they were okay” (February 22, 2012). Whatever they did to make things better for their child, was their joyous reward.

While the responses given by the parents were often a function of their child’s age, they were fundamentally quite similar. The parents emphasized they did everything possible to take the child’s mind off their ordeal, and that represented a distraction for both the parent and the child. Parents with younger children saw a great benefit in having scheduled playtime to be an important part of their lives. For the somewhat older children, a pro-active follow-through approach was utilized.

**Emphasizing Play**

As simple as the word sounds, play was an essential part of helping both the parents and the child cope with their present ordeal. One of these parents was Participant D, whose daughter was three-years-old at the time of her diagnosis. She brought photos from her previous albums to narrate the therapeutic importance of a doll called “Purple” which was a gift to the child, but which turned out to be so much more than just another toy. One of the hospital staff members recommended that the doll serve as a healing companion for the child and the parent.
Participant D noted that Purple went through everything with her daughter. Purple gave company to her daughter and was always there to share her daughter’s ordeal. This simulated and ongoing relationship between the child and the doll made it easier for the child to accept treatment protocols, wear masks, and do other unpleasant tasks. Her daughter knew that where she went, the doll was just a short string length behind, and always there for comfort.

*Para mí fue muy importante porque ella tenia con quién compartir de alguna forma lo que sentía.*

To me it was important that she had someone to share with what she was feeling. (Participant D, February 13, 2012)
She also mentioned that nurses encouraged and understood the simulated relationship between the child and Purple, and they encouraged the child to use the doll to express her own thoughts.

The doll accompanied the child everywhere. If the child had to go out in public, then Purple also had to be there, wearing the exact same thing as the child.
Siempre que la sacaba las dos llevaban mascarilla. O cuando salíamos a veces las enfermeras se la ponían porque le pedía también a las enfermeras que le pusiera la máscara a su muñeca porque ella traía mascarilla. Entonces fue una terapia para ella. Todo lo que pasaba ella, pasaba su bebé entonces ella no estaba sola. Por eso es importante que siempre tiene uno que llevar un osito o algo con el que el niño se sienta a gusto.

Participant D also emphasized how helpful toys can be to a young child undergoing cancer. The toys can provide companionship and comfort and be a participant in the child’s ordeal. While most parents had little control over the cancer treatment regimens, they all figured out ways to make the journey a bit easier on the child and on them.

Participant P, who brought a photo from her previous albums, gave a Woody doll to her son which provided companionship while her child was undergoing check-ups. Toy Story’s Woody helped her son overcome his fears when a nurse suggested they use it: “He would only let himself after they took Woody’s blood pressure and that’s the only way he would do it so that was another way that helped him cope with it” (Participant P, February 26, 2012).
Another parent of a young child attributed her son’s enhanced comfort to his Bullseye (another *Toy Story* character) and his blanket. These artifacts allowed the children some degree of environmental familiarity even when they were away from home.
Another playtime approach that some parents spoke of was the use of tricycles. These simple tricycles helped both children and parents cope with the ordeal of cancer. Parents mentioned that some of the local medical staff encouraged the use of tricycles at the hospital. Participants D and P used photos from their previous albums, emphasizing the tricycle’s role in the healing process.
Participant P’s narration consisted of how her son could not walk and how the tricycle allowed him to exercise without being cumbersome. For both moms it was important to get their children out of the hospital room and walk. They both described the claustrophobia associated with staying in a single room for long periods of time. Tricycles were about mobility and represented freedom.

This tricycle stayed with us the whole six months…it would help me cope also because we would get out of the room and he would ride…I would not be just stuck in the room all day and just to see him pedal the tricycle was just amazing (Participant P, February 6, 2012).
Participant D noted that chemotherapies had such strong side effects that it would force the child to remain in bed. Tricycles provided a playful avenue to regain movement and mobility.

*I sat her down on the tricycle, tied her feet to the pedals and I took her throughout the entire hospital and that helped her a lot…it helped me because I didn’t have to stay in the room with her.*

*(Participant D, February 13, 2012)*
It is worth noting that Participant D had to take her child out-of-town for treatment. What she mentioned in her narrations was that in this other Texas-based hospital no tricycles were allowed:

_Allí el área donde los tienen es muy restringida. Allí no más las terapistas son las que van. El cuarto es muy grande pero no tienen triciclos entonces yo me acordé lo que el doctor dijo, ‘No puede caminar, póngale un triciclo,’ y anduve pidiendo un triciclo ahí en el hospital y no me lo consiguieron._

(Participant D, February 13, 2012)

**Pro-active Follow-Through**

For parents who had somewhat older children i.e., those who were no longer into dolls and teddy bears, some other alternative ways of coping surfaced. Participant I coped with her son’s Acute Lymphoblastic Leukemia (ALL) by taking a highly pro-active approach to managing her son’s illness, helping both herself and her son to cope with the cancer ordeal.
Participant and Child Updating his Treatment Calendar (permission granted by participant to use photo)

Close-up of Child’s Treatment Calendar (permission granted by participant to use photo)
Entonces yo le tengo a él sus calendarios.
Yo desde un principio en el protocolo voy apuntando lo mismo que el doctor. Como decir en Febrero 20 le tocó esta medicina y esta también, y eso lo voy poniendo...el día 14 le dió dolor de cabeza y le hablé al doctor y quiso que lo llevara y le recetó esto y apunto el nombre de las pastillas.

So I have his calendars. Since the very beginning, in the protocol, I write the same thing the doctor does. For example, February 20th this medicine was given and I write that down...the 14th he had a headache and I called the doctor and he wanted me to take my son in and he gave him these pills and I write that down.

(Participant I, February 22, 2012)

Participant I derived tremendous satisfaction and peace from knowing that she kept record of everything, and followed up on all matters of importance to her son’s illness. She noted that there were several times when her record-keeping, cross-checking, and pro-active follow-ups avoided problems and screw-ups. She commented:

A mí me han tocado ocasiones que me ha dicho el doctor o las enfermeras ‘Le toca esto,’ ‘No, no le toca esto,’ porque yo estoy al pendiente.

I have had occasions in which the doctor or the nurses say, ‘He needs to take this,’ ‘No, he doesn’t,’ because I’m aware of it.

( Participant I, February 22, 2012)

Sharing and Solving by Being Verbally Proactive

While Participant I had photographs of calendars and other organizing devices as a representation of her coping, other participants mentioned the importance of being verbally proactive. They did not have any photos of being verbally proactive, but their narrations about other photos were revealing. Participant P noted how she was verbally proactive after she came
to know that one of the moms at the pediatric oncology clinic did not know what medication her son was receiving:

…I told her ‘You need to be aware of what they’re putting in your child because they make mistakes, we’re all human.’ I think that’s the only control we have over them, that we know they’re getting what they’re supposed to be getting…and right there and then I thought okay God thank you. I mean when you first start you think why me, why us, but then there comes that moment where you’re like okay that’s why cause I was going to talk to her and let her know what’s going on because she wasn’t even aware (January 26, 2012).

Other parents agreed with this sentiment and noted how important it was to be on top of their child’s diagnosis, treatment, medications, doctor’s visits, precaution regimens, etc. Things fall through the cracks, medical staff included, so it fell on the parents’ shoulders to keep track of what was going in.

**Honest Communication**

Almost all the parents emphasized the importance of being honest with the child about what they were going through, even with very young children. There was nothing to hide, as the physical and emotional ordeal associated with pediatric cancer treatment regimens is both real and palpable.

Participant P noted that she may have lied or minimized what her child was going through initially, but she saw that nothing good came of it (January 26, 2012). She changed her stance and told her son as much as she could possibly tell him. Other parents agreed that while at first it may be uncomfortable to tell children the truth, it is necessary:
Al principio tal vez no quería pero a mí se me hace que es mucho mejor decirles la verdad que ocultarles porque si en un momento dado ella se pone más mala el momento que está ocultando se me hace que le pegaría más duro el que se lo ocultamos a que ella supiera lo que tenía.

At first maybe I didn’t want to, but I think it’s a lot better telling them the truth instead of hiding it because if she gets worse I think it’ll hit her harder that we hid it from her instead of telling her the truth.

(Participant R, February 20, 2012)

Other caregiving parents also narrated instances where being open and honest played a key role in building and maintaining the trust between them and their child, and how critical that was in helping them cope. Participant M2 strongly advocated for honesty:

I rather be honest with them than for them to look at me like, I can’t trust you. A lot of parents, I think, lie to their kids. A lot of the time they think they’re protecting them but they’re not (February 29, 2012).

Another participant took a “learning” approach to foster honesty. For her own sake and for her child she needed to learn and understand what platelets, blood transfusions, chemotherapy, and other procedures were all about. Now that her child is doing better, and has been out of treatment, they can revisit how her child was doing previously and how far they had traveled in healing the afflicted body.
Entonces yo le expliqué a mi niña de dónde venían las plaquetas, de donde venía la sangre, a quien se la sacaban y que viera como me la estaban sacando a mí, para que ella entendiera que nomas es de ir al laboratorio, sacálas, y ya. Es un proceso, es por gente buena que va y la dona.  

So I explained to my daughter where platelets and blood came from, who they took it out of and for her to see how they took them out of me so she understands that it’s not just going to the laboratory and asking for some. It’s a process; it’s because of the nice people who donate.  

(Participant D, February 13, 2012)

Participant D not only explained about blood donation to her daughter, by also reinforced through these acts to become an active donor. She mentioned how playing an active role as a “teacher-learner” helped her cope. She feels happy and proud that she continues to donate blood and is doing something to better the situation even when her child is already out of treatment. Her daughter’s picture on the wall enables health workers to show blood donors one of the children who received the blood and platelets they donated. In essence, Participant D is herself a role model of openly and honestly sharing information with her daughter and other stakeholders.

In sum, parents employed several practices to help their children and themselves cope with the ordeal of their child’s cancer. The use of dolls and toys as comforting artifacts was clear. Pro-active follow-through actions (both verbal and otherwise) were important to track progress, reduce medical errors, and gave parents a sense of control in a situation where many things were not in their control. Parents emphasized the importance of openly and honestly sharing with their child what was going on and what to expect. In essence, the wellbeing of parents was reflected in “if the child is okay, then I’m okay.”
Communicative Behaviors and Practices for Emotional Coping

RQ4 asked: What are some communicative behaviors and practices that aid family members in emotionally dealing with the child’s cancer?

What differentiates this section from the previous section is that the coping behaviors narrated here primarily meet the emotional, affective, and spiritual needs of caregiving parents. Key behavioral practices in this realm include communicating with others for support, receiving help and guidance from family and “surrogate” family friends (e.g., hospital staff), and practicing one’s faith.

Communicating for Support

Caregiving parents emphasized the importance of communicating with others about what was happening as a way of expressing, sense-making, venting, and seeking support. Many of the parents noted that they found such support among friends and family, and institutionally at Candlelighters and in hospitals. Just plain simple talk with others had a healing effect.

Participant P2 was the only participant in the study who had lost her child to cancer. She coped with her loss by being able to find an expressive outlet. She became active in meetings held at Candlelighters where she and other moms could talk about their emotional status and discuss topics like *quehaceres no cumplidos* (unfinished chores). Although Participant P2 did not take a photograph of the sessions at Candlelighters, she took one of her weekly rosary prayer meetings. These meetings also provided an opportunity for her to meet people, talk about life, love and death, and realize that she is not alone in her suffering. She noted:
Participant D at the Weekly Rosary Prayer Meeting (permission granted by participant to use photo)

_Eso me ha ayudado mucho porque va uno y rezas y luego te quedas a platicar un ratito y te das cuenta que no no más tú tienes problemas, que toda la gente tiene._

This has helped me a lot because you go and pray and after you stay and talk for a bit, you realize you’re not the only one with problems, everybody has them.

( Participant P2, February 24, 2012)

Another participant also emphasized, through a photograph she brought from her previous albums, how Candlelighters played a big role in bringing families together and giving them a common platform to discuss their woes, struggles, and triumphs. This common space was non-judgmental and compassionate as all those who participated were facing similar challenges and interconnected through a common experience. In her words:
Participant P and Other Moms from Candlelighters Celebrate Mother’s Day (permission granted by participant to use photo)

Candelighters took us on Mother’s Day to eat. These are all moms of patients with cancer. So we talked about what we were going through so that definitely helped me cope. I mean, that right there told me ‘you’re not alone. There are other people in your same situation’ (Participant P, February 6, 2012).

The above responses emphasized the importance of communicating with others in order to feel supported and to receive encouragement as a parent who has a child with cancer. Participant J, also used a photo from her previous albums and noted that going to parents (or couples) sessions with her husband helped both her and her husband.
While several parents photographed themselves with others to demonstrate the importance of communicating, one participant who was not able to do so during her child’s illness, found herself doing so now. In her narration, she emphasized the need she had for communicating with others when her child was sick, and so now she offers advice to those, who like her, do not have anyone to talk to:

…find somebody close to talk to whether it’s your husband or the opposite, your wife or your sister or your mom, I would recommend to set up an appointment with somebody…whether here with Candlelighters or another provider so you can talk, so you can cry with somebody cause I think it’s important because when you talk about it later on then you’re like me, that you can’t cry even though you want to…you hold it all in…so I think that’s one of the negative things that you cope cause this is about coping (Participant M2, February 29, 2012).
A Participant Learning in Class at a Local Chapter Organization (permission granted by participant to use photo)

Participant in Arts and Crafts Class at a Local Chapter Organization (permission granted by participant to use photo)
Participant L2 and M2, had photo representations to emphasize what they do now given their children are doing much better. To break the monotony of the day (now that they have more time) they have enrolled in classes where they can not only take their children but also at the same time learn skills in parenting, arts and crafts. Most participants found out about these classes through flyers they received from their children’s school. This provided a “distraction” and an opportunity to “not be at home doing nothing” (Participant L2, February 23, 2012; Participant M2, February 29, 2011).

Participant Writing in her Therapy Journal (permission granted by participant to use photo)

Participant P2 coped with her ordeal by having a conversation with herself through the medium of writing. This approach was suggested by her child’s therapist. When the opportunity of talking to others was not available, Participant P2 wrote in her journal:
Que me pusiera a escribirle cartas a él o cartas de como me siento y hubo un tiempo que si lo hice mucho y me ayudo pero ya después ya lo deje y has de cuenta como que ando así recayendo otra vez y dije ‘no, ya tengo que escribir.’
I wrote letters to him or about how I felt. There was a time where I did it a lot and it helped me but after a while I stopped. And now it’s like I’m falling again so I’m like ‘no, I have to start writing.’

(February 24, 2012)

Receiving Support from Family

Every narration and photograph in the present study noted the importance of receiving family support in being a parent of a child with pediatric cancer. One photograph did stand out in this regard and it was taken by the only participating couple in the study, Participants L and J2. This photographed was used to show just how strong a tie is needed between family members to cope with this family ordeal.

Participants Join Hands with their Children to Keep Strong (permission granted by participant to use photo)
“This is just who we are,” Participant L (February 9, 2012) said. Without the support of the whole family it would have been impossible to face cancer. “You’re not alone,” was another sentiment expressed by Participant M who had her parents, sister, and brother-in-law take turns watching her child at the hospital while she and her husband had a meal or ran errands (February 28, 2012). Participant R also expressed how grateful she is to have her children and husband help her as they go through the process of treatment for her daughter and hoping to find her a liver donor (February 20, 2012). These participants also mentioned how they could depend on receiving help from family members and could rely on them when things got worse. They had family members to speak to when feeling depressed and/or overwhelmed. Pictures with family members, great-grand parents, grandparents, parents, children, aunts, uncles, brothers and sisters emphasized the same message, “We’re not alone.”

**Support from Surrogate Family**

In addition to support from the immediate family, there were other people who helped caregiving parents to cope with their child’s cancer. These included medical staff such as doctors, nurses, therapists, technicians, and social workers. These people “became family” and helped parents above and beyond what was expected of them (Participant M, February 28, 2012). One parent touched on the fact that it is important to create positive relationships with the staff:

They help us take care of our child, they help us feed our child, give them their medicines, take them to the restroom, they help us in every situation. So if you take the time to become friendly with them and treat them like family, like a friend, then you can count on them and they will help (Participant M, February 28, 2012).
As parents and their sick children often ended-up staying in hospitals for months, the medical staff became their second family (or “surrogate”) family. They were ones that parents relied on, depended on.

![Therapist Playing and Engaging with Child](image)

Therapist Playing and Engaging with Child (permission granted by participant to use photo)

For Participant L2 the photograph brought in from previous albums was to represent occupational therapy but the narration went beyond that. This picture, though taken in the past but which still represented her being able to cope, brought the mention of a specific nurse who always helped Participant L2 with anything and everything. She would give her caregiving tips and taught her how to do things that would benefit her child. “Yo aprendi de ellas (I learned from them),” (Participant L2, February 23, 2012).

Another communicative behavior and practice by the medical staff that aided participants was narrated by Participant J2. He mentioned his daughter’s favorite nurse and how close they
have become to the point where the child now looks forward to seeing her regularly. Participant J2 mentioned specific communicative practices the nurse engages in that help him cope emotionally. This nurse made the child “…feel comfortable…she would talk to her, ‘What do you want to be when you grow up?’ She (nurse) would just take her (child) mind off of what was happening,” (Participant J2, February 6, 2012). She would also be honest with the child which made it easier on him as a parent to deal with what was going on because the nurse was not just being honest to his daughter, but to him as well.

Most participants mentioned having a closer relationship with nurses than they did with doctors. The participants were okay with it realizing that doctors have more children to attend to, and therefore could only have limited time with them. One exception was the doctor mentioned by Participant R. This doctor would come in, sit down on the patient’s bed and in a non-rushed manner explain to the pre-teen what was going on with her health (Participant R, February 20, 2012). According to the participant, this doctor would treat her child as what she was, a pre-teen, not just another patient.

Doctors and Child Share Smiles at the Hospital (permission granted by participant to use photo)
Parents also pointed out how helpful it was that the professional medical staff never seemed to say “no.” The staff always welcomed taking pictures (see photo above) with the children, and an array of photographs that were narrated proved just that. Photographs of children posing with their nurses, doctors, therapists, and social workers, like the photo above brought in from a previous album by Participant P, came up often because of how these people treated children. The medical staff always kept the child’s best interest at heart. Some narrations described how nurses would secretly allow family members to see the child as long as the child’s health was not put in jeopardy. The parents also liked when social workers would participate in activities with the children by playing games or creating artwork.

Nurse Helping Child add on to his Beads of Courage (*permission granted by participant to use photo*)

The degree of love and support these parents received from the medical staff was something that all participants never grew tired of discussing. They trusted their child’s life to
these professionals and so this relationship was special at many levels. A couple of parents emphasized how each parent should build a strong relationship with the medical staff, so that the relationship extends beyond the hospital.

**Practicing One’s Faith**

![Virgen de Guadalupe Statue in Living Room](permission granted by participant to use photo)

Faith was noted as the number one factor that aided parents in emotionally dealing with their child’s cancer. In every narration, even if it did not directly pertain to aspects of faith, the mention of leaving their child’s fate in God’s hands was present. They also attributed their strength to keep going through every treatment, surgery, doctor’s visit, and so on to their faith.
Parents also mentioned using the hospital chapel when they needed a chance to cry because crying was also another way they coped with the situation. “It’s okay to cry,” Participant P emphasized (February 6, 2012). Several other parents gave similar responses.

Child Wearing a Homemade Rosary (permission granted by participant to use photo)

Child Smiling Next to Faith Poster (permission granted by participant to use photo)
The narrations to the photographs above, one of which was taken before the study, showed that faith was important not just for the parents, but also to the sick child and their siblings. According to Participant I, faith is what gives her son the strength to keep going and to never give up (February 6, 2012). Participants L and J2 said that faith allowed them to remain strong for their child so she felt that a higher power was watching over her (February 6 & 9, 2012). Participant P noted that when her child was first diagnosed, her first thought was to go to the hospital chapel with her child and pray (February 6, 2012). Interestingly, even parents who did not consider themselves religious still attributed their child’s wellbeing to faith and prayer.
Summary

In sum, answers to the research questions reveal numerous difficulties parents’ faced and specific communicative behaviors and acts that helped the parents cope with pediatric cancer. These were captured through photographs and narrated by the participants.

Many parents chose to photograph their child’s ordeal to be able to explain to the child what they experienced when they grow up. Some parents were openly emotional and cried during narrations while others preferred a more matter-of-fact approach of doing what needed to be done in the moment. Both represented different kinds of coping approaches.

Parents emphasized the difficulties and dilemmas they experienced while their child underwent cancer treatment. Many of these communicative difficulties and dilemmas arose from public ignorance. Respondents also commented on limited or insufficient spousal communication. These parents spoke about not having the type of communication they wished to have with their spouses, but others preferred compartmentalizing both hospital and home life, feeling that it benefitted them to only talk about the child’s illness when necessary. Another difficulty faced by parents of pediatric cancer patients was being the caregiver of other children too. Due to the ill child demanding most of the parent’s attention, caring for the other children was always challenging.

Parents also highlighted communicative behaviors and practices for effective care of the ill child. Emphasizing play with artifacts like dolls and tricycles offered both the parent and the child a level of comfort. A pro-active follow-up approach involving being on top of treatment regimens and following through with medical staff was utilized by some to feel a degree of control in caregiving. This also led parents to engage in sharing their experiences with other parents and solving any potential problems by being verbally pro-active. Parents also
emphasized honest communication among them and their children in order to keep building and maintaining a strong relationship.

Parents were able to effectively deal with the emotional and affective aspects of caregiving by communicating with others for support, receiving help and guidance from family members, being cared for by “surrogate” family (e.g. hospital staff), and practicing one’s faith.

Simply put, talking with others as a caregiving parent provided a sense of safety, security, and release. When possible, breaking routine and embracing productive distractions for themselves and their ailing children helped them to move forward in this difficult journey.
Chapter 5

Conclusions

Despite being the second leading cause of death among children under the age of 15, pediatric cancer continues to be a taboo subject in the U.S. With improved survival rates, there is increased need for people-at-large to learn what caregiving parents and children go through in order to cope effectively with their ordeal. Caregiving parents have accumulated a lot of wisdom about what communicative behaviors and practices work for them and their afflicted children. In the present study, this “expertise” that lies with the parents was allowed to be voiced through Photovoice. Their difficulties, dilemmas, coping behaviors and strategies were elicited in photos and narrated in their voice.

Twelve parents of children currently undergoing treatment or those who had gone through treatment for pediatric cancer participated in this study. Candlelighters helped access and invite them into the study.

Many parents recorded their experience with pediatric cancer by taking pictures so that they could share with their children, once they grew up, what they had gone through. One of the parents emphasized that she took pictures even before her son was diagnosed and once the diagnosis was given, it only seemed natural for her to continue to document this ordeal. Another parent took pictures to document the crests and troughs from one day to the other. While most parents agreed that taking pictures of their children was an important way of documenting their journey, they talked about it with differing levels of emotional intensity. Some parents openly cried while others were more matter-of-fact in their narrations. Importantly, the display of emotion (or not) represented a coping strategy.
Parents of pediatric cancer patients also spoke about communicative difficulties and dilemmas in light of public ignorance. As much as parents tried to protect their child, it was difficult when others in the public stigmatized them or thought of their illness as being contagious. Respondents also emphasized that they dealt with limited or insufficient spousal communication by concentrating, instead, on their child’s wellbeing. While some preferred to compartmentalize hospital and home life, most of the mothers aspired for richer communication with their husbands. Parents also mentioned that because their attention was on the ill child almost 100% of the time, their other children obviously were neglected. Parents tried to make up for it in creative ways. Some jealousy among siblings was to be expected for not getting as much attention, and surfaced in some of the narrations.

Emphasizing play by using dolls and tricycles helped both children and their parents cope. These artifacts allowed children who were away from home for long periods of time to have a sense of familiarity and comfort. Tricycles allowed parents and children to experience life outside the hospital room, giving them a playful freedom. Parents of somewhat older children utilized a pro-active follow-through approach that allowed them to keep a record of, and track the progress of, everything pertaining to the child’s illness. One parent kept track of everything by transferring information onto a calendar while others chose to be conversationally (or verbally) pro-active. This pro-active follow-through allowed them to stay on top of the child’s treatment, medication, and to help other parents become aware that by keeping track of medications, treatments, etc. they could prevent a medical mistake from happening. Parents believed that honest communication about what pediatric cancer entailed was key to building and maintaining the trust between parent and child.
Another major communicative aspect of coping with pediatric cancer for the respondents was being able to speak to others who shared similar experiences. Candlelighters was a major facilitator of this as it allowed that space for parents to gather and talk to each other about their difficulties, dilemmas, emotional strains, and mundane topics like unfinished chores. For some parents, opportunities for mixing with others were limited while their child was ill, but now, with their child doing better, they attended classes in parenting skills, arts, and crafts. One parent talked about the importance of self-talk, opting to write a daily journal.

Support also came from family and from the “surrogate” family (doctors, nurses, therapists, and social workers). Parents expressed how they were able to grab a quick bite to eat while their family watched over their child, and how family members listened to them when they were feeling depressed and/or overwhelmed about the situation. The “surrogate” family was also present to help parents cope by going above and beyond what was expected. Many parents expressed that doctors, nurses, therapists, technicians, and social workers were ever present and how they taught them to better care for their children. Parents also emphasized how important it is to establish a positive relationship with the “surrogate” family. Parents attributed their own strength and their child’s strength in coping with the ordeal to their spiritual faith. “It’s what keeps us going,” they noted.

In sum, the answers the parents shared emphasized the importance of recording their journey through pediatric cancer. While parents faced communicative difficulties and dilemmas as a result of public ignorance, or not being able to fully count on their spouses for support, they found solace in focusing on their child’s care and in ensuring their wellbeing.
Implications

The coping strategies uncovered in the present study can help other parents who have a child diagnosed with pediatric cancer, or any other disease for that matter. The findings can also help organizations like Candlelighters who work with children and their families. The use of Photovoice allows the embodied yet latent expertise of the caregiving parents to surface. They may not have a medical degree, be a trained psychologist or a therapist; but these are the caregivers who work endlessly, day in and day out, to take care of loved ones in times of adversity.

The present research holds practical value and implications for scholars, practitioners, and caregivers. Findings from the present research can be disseminated through publications and the coping behaviors described by parents can be widely shared on pediatric cancer support websites and through social media (e.g., Facebook and Twitter). There is also potential for video-based dissemination of these findings. As a next step, consideration has been given to videotaping some of the key behavioral strategies for coping and creating a Coping Wall on Facebook and YouTube to share with a wider public.

Learning and Next Steps

Pediatric cancer affects all nationalities, races, and social status. It affects thousands of children a year and takes a toll on their caregiving families. Because of the social tabooness of the topic, and limited public discourse on it, parents of newly-diagnosed children face a tough road ahead – full of doubt and insecurities.

This research project tried to unpack some simple solutions that have already worked for other parents in overcoming doubts, insecurities, and dilemmas in caring for a child with pediatric cancer. In the process, certain communicative behaviors and practices were discovered
that allowed for better clinical and relational outcomes. Simple ideas like dolls that serve as alter-egos for the afflicted child, or riding a tricycle, or praying together in a chapel or at the home alter made a big difference.

As a researcher, this project represented a “journey” for me, as well. Having lost my mother to cancer when I was 13-years-old, I was personally invested in the topic. It brought back memories of family struggles and difficulties in caregiving, and revived memories of deep personal loss. The mere thought of starting this research was overwhelming, and the thought of “Am I strong enough?” never seemed to completely go away. Yet, something just gave me the energy to keep moving forward. It was in some ways a part of my healing.

I also realized how adaptable a researcher needs to be during the evolving research process. My initial plan was to screen participants for the study based on certain criteria. I soon realized such was going to be difficult as I had not taken into consideration the parents’ schedules, treatment regimens, doctor’s visits, and the like. Because of that realization, I opted to open the study to any caregiving parent who could make time to participate. That also led to another shift. Initially, I only wanted those parents whose child was currently going through treatment to participate. But those are the families who are the busiest and whose children are most susceptible to infections because of compromised immunity. In hindsight, including parents of children who had finished treatment opened the doors to many answers that might not have otherwise come up.

I also discovered how disclosure begets disclosure. In order to get participants to trust me with their time and information it worked best if I told them my story. I would confide in them how my mother had been diagnosed with breast cancer and how, like them, I was thrown into the situation without knowing what to do. They seemed to appreciate my personal
investment, validate my embodied experiences, and welcomed me into their lives. Having established that trust in our relationship did not mean that there was a cookie-cutter way for me to gather my data. With each respondent, it was different. The order of photos and narrations changed quite dynamically from one respondent to another. What was common was that one narrated thought often lead to another, and so on. While I had a slew of follow-up probes for each narration, many times a single narration answered all my questions. Many a time, I probed further in ways that was hard to script in advance.

I believe this research has the potential to be expanded in many ways. One way of further expanding this research is to allow the children to participate in this data-gathering and sense-making exercise. We have some ideas on how parents effectively deal with pediatric cancer, but it would be nice to get the child’s perspective for an even richer understanding. Also other possible extensions of the study would be to look at how siblings, extended family and friends, and medical staff cope with pediatric cancer. Cancer touches the lives of not just the child and the caregiving parents, but of the community at large. It would be valuable to find out how children are impacted and how those who work for these children are also affected. It would provide for a more richer, nuanced, and comprehensive understanding of how healing works in the face of adversity, and especially what role communicative practices and actions play in this situation. The lessons learned will go beyond pediatric cancer and contribute to our growing understanding of health communication as a field of study and practice.

As noted previously, health and well-being are not just about following medical regimens and routines. Communication is central to accessing and making sense of health information, and provides the basis for emotional and psychological well-being. Communicative practices
become especially important during caregiving, when seeking social support, and when decisions have to be made about what to do (or not do) next.

Candlelighters has proposed that based on this research and its findings, a small training course be designed and offered to parents of children with pediatric cancer so that they too can learn from their peers. Perhaps it would empower them to try out new coping ideas that they may not have considered before. The findings of this study also hold value in pediatric oncology units in hospitals, and other cancer networks who work with caregiving families. Pediatric cancer deserves more airtime in public discourses and spaces. Cross-sharing of experiences, learnings, and strategies are important ways of coping and healing, especially when a child’s life and welfare is at stake. I hope this study makes a small contribution in that direction.

At a deeply personal level, I sense that my mother is smiling down. While she in not here to read this study, she was with me throughout the process.
Appendix A

Informed Consent Form (ENGLISH)

University of Texas at El Paso (UTEP) Institutional Review Board

Informed Consent Form for Research Involving Human Subjects

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**Protocol Title:** Photovoice with Pediatric Cancer Parents: Communicative Behaviors for Effective Coping

**Principal Investigator:** Gabriela I. Morales

**UTEP Department:** Communication

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In this consent form, “you” always means the study subject. If you are a legally authorized representative (such as a parent or guardian), please remember that “you” refers to the study subject.

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1. **Introduction**

   You are being asked to take part voluntarily in the research project described below. Please take your time making a decision and feel free to discuss it with your friends and family. Before agreeing to take part in this research study, it is important that you read the consent form that describes the study. Please ask the study researcher or the study staff to explain any words or information that you do not clearly understand.

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2. **Why is this study being done?**

   You have been asked to take part in a research study of “Photovoice with Pediatric Cancer Parents: Communicative Behaviors for Effective Coping.” Approximately, 12 participants will be enrolling in this study at Candlelighters of El Paso. You are being asked to be in the study because you are the parent of a child currently undergoing treatment for pediatric cancer for at least three months or more.
   
   If you decide to enroll in this study, your involvement will last about one week and a half.

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3. **What is involved in the study?**

   If you agree to take part in this study, the researcher will ask that you take photographs with a disposable camera provided by the researcher in order to obtain your responses and experiences regarding coping with pediatric cancer. Once the disposable cameras are returned after one week, the researcher will require that you select 6 to 8 photographs to narrate to the researcher regarding their significance to you. The narrations you provide will be audio recorded.
4. What are the known risks of this research?

There are no known risks associated with this research.

5. What will happen if I am injured in this study?

The University of Texas at El Paso and its affiliates do not offer to pay for or cover the cost of medical treatment for research-related illness or injury. No funds have been set aside to pay or reimburse you in the event of such injury or illness. You will not give up any of your legal rights by signing this consent form. You should report any such injury to Gabriela Morales, gmorales7@miners.utep.edu, (915) 274-9680 and to the UTEP Institutional Review Board (IRB) at (915-747-8841) or irb.orsp@utep.edu.

6. Are there benefits to taking part in this study?

This research may help us to understand, directly from the source, what parents with pediatric cancer children go through in order to cope with their child’s illness.

7. What other options are there?

You have the option not to take part in this study. There will be no penalties involved if you choose not to take part in this study.

8. Who is paying for this study?

The expenses for this study are minimal; expenses will be covered by the researcher.

9. What are my costs?

There are no direct costs.

10. Will I be paid to participate in this study?

You will not be paid for taking part in this research study.

11. What if I want to withdraw, or am asked to withdraw from the study?

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you do not take part in the study, there will be no penalty.

If you choose to take part, you have the right to stop at any time. However, we encourage you to talk to a member of the research group so that they know why you are leaving the study. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them.

The research may decide to stop your participation without your permission, if he or she thinks that being in the study may cause you harm.
12. Who do I call if I have any questions or problems?

You may ask any questions you have now. If you have questions later, you may call Gabriela I. Morales at (915) 274-9680, and gmorales7@miners.utep.edu.

If you have questions or concerns about your participation as a research subject, please contact the UTEP Institutional Review Board (IRB) at (915-747-8841) or irb.orsp@utep.edu.

13. What about confidentiality?

Your part in this study is confidential. None of the information will identify you by name without your permission. You may review any information provided by you before publication. The audio recordings of the narrations provided by you will only be assessable to the researchers participating in this study. All photographs and recordings will be stored in a special hard drive and kept at the researcher’s home in a locked cabinet. All recordings and photographs will be protected until thesis is published and afterwards, all audio recordings will be deleted/erased from the hard drive. The recordings will serve to accurately verify narrations and discussions.

14. Mandatory reporting

If information is revealed about child abuse or neglect, or potentially dangerous future behavior to others, the law requires that this information be reported to the proper authorities.
15. Authorization Statement

I have read each page of this paper about the study (or it was read to me). I know that being in this study is voluntary and I choose to be in this study. I know I can stop being in this study without penalty. I will get a copy of this consent form now and can get information on results of the study later if I wish.

(Check one)

☐ Yes, you have my permission to publish these photos along with our information.

☐ Yes, you have my permission to publish these photos without our information.

☐ No, you do not have permission publish our photos or information.

☐ I want this research to be meaningful to others and would want to further discuss with you what an appropriate way of handling photos and personal information may be.

☐ Yes, I would like to be contacted in case of a future related or follow-up study.

☐ No, I would not like to be contacted in case of a future related or follow-up study.

Participant Name: __________________________________  Date: __________

Participant Signature: ________________________________  Time: __________

Consent form explained/witnessed by: ________________________________

                          Signature

Printed name: Gabriela I. Morales ________________________________

Date: _________________  Time: _________________
Appendix B
Consent Form (SPANISH)

University of Texas at El Paso (UTEP) Junta de Revisión Institucional
Formulario de Consentimiento en Español para Estudios con Participantes Humanos

Título: Photovoice y los Padres con Hijos con Cáncer Pediátrico: Estrategias de Adaptación por Medio de Conductas Comunicativas.

Investigador(a): Gabriela I. Morales

Departamento de UTEP: Comunicación

1. Introducción
Usted está siendo invitado a participar voluntariamente en el proyecto de investigación que se describirá a continuación. Por favor, tómese su tiempo para tomar una decisión y sientense libre de hablar con sus amigos y familiares. Antes de aceptar participar en este estudio, es importante que usted lea con mucho cuidado el formulario de consentimiento que describe el estudio. Por favor, pregunte a la investigadora principal del estudio o el personal del estudio que le explique cualquier palabra o información que no entienda claramente.

2. Porque se está realizando este estudio?
Usted ha sido solicitado(a) para participar en el estudio “Photovoice y los Padres con Hijos con Cáncer Pediátrico: Estrategias de Adaptación por Medio de Conductas Comunicativas.”

Aproximadamente 12 personas van a participar en este estudio en Candlelighters of El Paso.

Usted ha sido seleccionado(a) para este estudio por que usted es padre o madre de un niño(a) recibiendo tratamiento para cáncer pediátrico desde hace tres meses o más.

Si usted decide participar en el estudio, su participación puede durar una semana y media (una semana para tomar fotos y otros días para la discusión de las fotos seleccionadas).
3. **Qué está implicado en el estudio?**

Si usted decide participar en el estudio, la investigadora principal le pedirá que tome fotos con la cámara desechable que ella le dará para poder obtener sus respuestas y experiencias referente a cómo se ha adaptado usted al cáncer pediátrico de su hijo(a). Después de una semana, las cámaras desechables se colectarán y la investigadora le pedirá que seleccione de 6 a 8 fotos para narrarlas a la investigadora referente a lo que significan las fotos para usted. Las narraciones serán grabadas con una grabadora de voz.

4. **Cuáles son los riesgos del estudio?**

   No hay ningún riesgo asociado con el estudio.

5. **Qué va suceder si me lastimo o lesione en este estudio**

   La Universidad de Texas en El Paso y sus afiliados no ofrecen pagar o reemplazar algún costo médico relacionado con problemas de salud en este estudio. No hay un fondo universitario para pagar por costos médicos dada la ocasión de que haya un problema médico. Al firmar el permiso del estudio no significa que va a prescindir de sus derechos legales. Por favor reporte algún problema médico a Gabriela I. Morales, gmorales7@miners.utep.edu, (915) 274-9680 y Universidad de Texas en El Paso Institucional Review Board (IRB) al (915) 747-8841, el correo electrónico es irb.orsp@utep.edu.

6. **Cuáles son los beneficios de este estudio?**

   Este estudio podrá ayudar al mejor entendimiento de cómo los padres de hijos con cáncer pediátrico se adaptan a la enfermedad de su hijo(a).

7. **Qué otras opciones hay?**

   Usted, bajo su propia voluntad, puede decidir si gusta o no gusta participar en el estudio. No hay ningún resultado negativo si no participa en el estudio.

8. **Quién está pagando por este estudio?**

   Los gastos de este estudio son mínimos. La investigadora se encargara de estos gastos.

9. **Hay algún tipo de gasto como participante?**

   No hay ningún gasto para el participante.

10. **Hay beneficios económicos al participar en el estudio?**

    No hay ningún beneficio económico como participante del estudio.
11. Que si tomo la decisión de no participar en el estudio, o me aconsejan que debo retirarme del estudio?

Su participación en este estudio es totalmente voluntaria. Usted tiene el derecho de escoger si participa o no participa. Si usted no toma parte en el estudio, no habrá penalización.

Si usted opta por participar, usted tiene el derecho de interrumpir (poner fin a) su participación en cualquier momento. Sin embargo, le recomendamos hablar con la investigadora para saber el por qué usted está dejando el estudio.

La investigadora puede también decidir terminar su participación sin su permiso si él o ella piensa que el estudio le puede causar daño.

12. A quién o a donde llamo si tengo alguna pregunta, duda o problema?

Si tiene alguna pregunta acerca del estudio lo puede hacer en este momento. Si tiene una pregunta después usted puede contactar a Gabriela I. Morales, gmorales7@miners.utep.edu, (915) 274-9680. Si tiene preguntas o dudas acerca de su participación como participante en este estudio, favor de contactar a UTEP Institutional Review Board (IRB) al (915-747-8841) o a irb.orsp@utep.edu.

13. Información sobre la confidencialidad?

Su participación en este estudio es confidencial. Ninguna información lo(a) identificara por nombre sin su permiso. Un alias será usado para identificalo(a). Usted podrá revisar las citas atribuidas a usted antes de la publicación de la tesis.

Las grabaciones de voz de las narraciones se acceden sólo por los investigadores que son parte de este proyecto. Todas las actas y las grabaciones se guardarán en un armario personal bajo llave en el hogar de la investigadora. Las grabaciones de voz digitales se protegerán bajo custodia hasta la fecha que la tesis se publique. Después las grabaciones digitales se eliminarán/borrarán. Las grabaciones serán utilizadas para verificar con exactitud las narraciones y discusiones acerca de las fotografías y actividades.

14. Tipo de Reporte Obligatorio

Si hay información sobre abuso de menores, o si hay probabilidad de este comportamiento hacia un menor, la ley exige que esta información sea reportada a las autoridades correspondientes.
15. Declaración de autorización:

He leído cada página de este documento sobre el estudio (o fue leído). Yo sé que en este estudio mi participación es voluntaria y puedo optar por participar o no participar en este estudio. Sé que puedo dejar de participar en el estudio sin penalización. Obtendré una copia de este formulario de consentimiento y podré obtener información sobre los resultados de este estudio más adelante si yo lo deseo.

(Marque uno solo)

☐ Sí, tienen mi permiso de publicar estas fotografías incluyendo nuestra información.

☐ Sí, tienen permiso de publicar estas fotografías sin nuestra información.

☐ No, no tienen mi permiso de publicar nuestras fotografías ni información.

☐ Quiero que este estudio sea de utilidad para muchas personas y quisiera explicarle cómo manejar sus fotografías e información.

☐ Sí, puedo ser contactado para un estudio similar o seguimiento de este estudio.

☐ No, no quiero ser contactado para un estudio a futuro ni para un seguimiento de este estudio.

Nombre del Participante: ______________________________ Fecha: ____________

Firma del Participante: ______________________________ Hora: ____________

Se explicó el formulario de consentimiento / Testigo: ____________________________

Firma

Nombre de molde: Gabriela I. Morales_______________________________

Fecha: _________________________ Hora: _________________________
Appendix C

Narration Guide Questions

Researcher/UTEP Photograph Narration Guide for Pediatric Cancer Parents

Q1: Why did you choose to talk about this specific photograph?

Q2: What does this photograph stand for?

Q3: How does this photograph express your difficulties and dilemmas that you confront every day when caring for your child?

Q4: How does this photograph show how you cope with your child’s illness?

Q5: What were other things you thought were important that you didn’t photograph?
References


Curriculum Vitae

Gabriela I. Morales

My ultimate goal is being able to take what I learned, not just as a graduate student, but as an undergraduate student, and apply the skills of communication, electronic media, production, audio engineering, and organization to a corporation whose purpose is to help those families going through cancer. I graduated with a Master’s Degree in Communication from the University of Texas at El Paso (UTEP) in May of 2012. My thesis, “Photovoice with Pediatric Cancer Parents: Understanding Difficulties and Communicative Behaviors for Coping Effectively,” looks into some of these communicative behaviors that aid families in being able to cope with cancer. This is an example of what I want to bring to a position. In 2009 I graduated Cum Laude with a Bachelor’s Degree in Electronic Media and a minor in Creative Writing from UTEP.

I started working in 2007 as an ESL tutor for the El Paso Independent School District. I tutored high school students in reading, writing, and test-taking. I also helped students in pursuing higher education by providing Q & A sessions when they completed their course work for the day. A couple of years later, I started working for KTEP 88.5 FM as a production assistant. This position also led to being a co-creator and co-leader of a student radio magazine called Miners News Radio (MNR) which was composed of only students and volunteers from the El Paso community. During my time as a production assistant for KTEP and an executive producer for MNR I produced local and nationally syndicated radio programming, coached students in interviewing techniques, production, reporting, and writing. I also recruited students for MNR and served as an audio engineer for both KTEP and MNR. This lasted from 2010-2011. After that I started working as a research assistant for Dr. Arvind Singhal in the
Department of Communication at UTEP. I helped in converting his archives to digital formats, updating the Social Justice Initiative website as well as Dr. Singhal’s own university website, and served as one of the coordinators for the first annual Changemakers’ Summit held at UTEP in the Spring of 2012.

During my graduate education I was inducted into the Alpha Chi National Honor Society for my 4.0 GPA. I also worked with many organizations on campus. One was in the Fall 2011 and was the first pioneering class of Media Changemakers. In that organization I was able to partake in projects that brought awareness to topics like cancer, the Mother-Daughter/Father-Son program at UTEP, Cesar Chavez, a shelter for homeless women and children, and others. I was also responsible for designing and creating products (bookmarks, cards, and t-shirts), audio engineering, photo-taking, and for creating and administrating Facebook, YouTube, and Twitter pages. Another organization was the Social Justice Initiative (SJI) in which I was part of the organizing committee for the first-ever Changemakers’ Summit in which educators, students, and other professionals came to El Paso to learn about Liberating Structures. For this event I was responsible for creating packets for our guests by providing complete biographies of the participants, creating the documents that held flight information and contact information, and providing other essential needs. Through SJI I was also able to be a products facilitator for the Nuestra Casa Initiative at the UTEP campus.

What I can offer an organization or company are being an advocate to initiative new and exciting projects, high determination and motivation, responsible individual, teamwork enthusiast. I am also proficient in MS Word, Powerpoint, Excel, Sharepoint, Photoshop, Adobe Reader, Adobe Audition, Cool Edit Pro and intermediate level skills in Adobe Illustrator, Adobe Design, Final Cut. I am also bilingual and speak fluent English and Spanish.