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Self-Portraits of Families with Young Adult Cancer Survivors: Using Photovoice

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INTRODUCTION

Prior to 1970, most children diagnosed with cancer had little hope of being cured. Thanks to advances in treatments, childhood cancer cure rates, as measured in 5-year survival, have reached 78% (Ries, et al., 2003). However, survival often comes at a price, namely *late medical and psychosocial effects*, which are defined as complications, disabilities, or adverse outcomes that are the result of the disease process, treatment, or both (Institute of Medicine, 2003). Although the lingering impact of cancer on surviving children is evident, there is little understanding of how long-term survivorship evolves as they grow into the later life stages and face different challenges in life. Furthermore, existing literature rarely reports on outcomes for racial/ethnic minority and low socioeconomic status populations, thereby limiting the usefulness of current research in application to a diverse and multicultural US population.

Existing literature on psychosocial outcomes and quality of life among young adult cancer survivors (YACS) show varied and inconsistent findings. On the one hand, *post-traumatic stress symptoms* have been reported in adolescent and young adult survivors (Hobbie, et al., 2000; Meeske, Ruccione, Globe, & Stuber, 2001). In contrast, other studies suggest that childhood cancer survivors are psychosocially healthier and more appreciative of life than the population norms or healthy controls (Elkin, Phipps, Mulhern, & Fairclough, 1997; Maggiolini, et al., 2000). Study findings often are influenced by the theoretical frameworks used to develop research questions. For example, studies utilizing stress-coping models often report psychopathology, whereas those derived from a strengths-based or resilience perspective identify factors associating with psychosocial adaptation and developmental growth. As Haase and Rostad (1994) aptly described, these two faces – “one of celebration and hope, and one of uncertainty and fear” - might both be true of survivorship. Thus, a comprehensive view of a complex human phenomenon such as cancer survivorship is not always captured in conventional hypothesis-driven deductive research approaches.

Current research on childhood cancer survivors consists of study samples comprised of predominantly Caucasian, educated, and middle class individuals and there is some literature suggesting racial/ethnic disparities in cancer experiences. For instance, in a longitudinal health outcome study on childhood cancer survivors (Meeske, Patel, Palmer, Nelson, & Parow, 2007) ethnic minority status was a significant predictor of worse quality of life. Involving minorities in survivorship research is important also because their views on the meanings of

cancer might be affected by their cultural lenses (Kleinman, Eisenberg, & Good, 1978; R. H. Wang & Martinson, 1996). Understanding the impact of cancer from their own perspectives would be beneficial in developing culturally-appropriate services for these underserved populations.

To further examine the impact of cancer from the perspectives of YACS and their families, the present study used an innovative qualitative methodology, Photovoice, for the purpose of eliciting participant-driven themes and having participants serve as the “experts” on their issues (Wang, Burris, & Xiang, 1996). The theoretical background and significance of Photovoice is discussed in the Methods section. The specific aim of the study is to report on themes that young adult cancer survivors and family members identified as relevant to their experience of cancer survivorship. When study participants tell their stories, they take ownership of the research, and a comprehensive picture of survivorship is expected to appear (Harrison, 2002).

METHODS

Participatory research methods have the potential to enhance our understanding of the complexity of cancer survivorship because it enables participants to make decisions and take active roles in the process of knowledge production and not function as passive subjects (Reinharz & Davidman, 1992). As a participatory research approach, Photovoice reflects Freire’s (1970) notions of empowerment education, feminist theory, documentary photography and health promotion (Wang & Burris, 1994; Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004). Firmly supported by theory, Photovoice allows individuals from varied social and economic groups to address their needs and concerns through the powerful means of producing visual images (Wang & Burris, 1997). The method has been used to investigate the social and environmental conditions and needs of underserved and marginalized populations, including the homeless (Wang, Cash, & Powers, 2000), rural village women (Wang, Burris, & Ping, 1996), youth in after-school programs (Strack, Magill, & McDonagh, 2004), and adolescent Latino immigrants (Streng, 2004).

This study included both survivors and family members in order to examine issues of convergence and divergence among family members who have experienced cancer in the family. We assume that there are similarities as well as differences in the experience of cancer’s impact between the young survivor and their family members. Indeed, studies suggest that patients and survivors often differ from one another as well as from other observers (parents, teachers) in terms of how cancer has affected their lives (Noll et al., 1997; Zebrack, Chesler, Orbuch, & Parry, 2002). By focusing on the family as context, data derived from survivors could be compared to data derived from family members, thereby offering opportunities for deeper insight into their individually distinct as well as collective survivorship experiences (Patton, 2002). The importance of family-based studies might be particularly great for understanding unique issues facing persons whose social identities are not well-represented in the reported literature, including groups defined by racial/ethnic status or sexual orientation. For example, dynamics of *familismo* and its influence on family psychosocial responses to childhood cancer are only recently emerging and offering a broader socio-cultural perspective on survivorship (Casillas, Zebrack, & Zeltzer, 2006).

Procedures

The Photovoice Project employed a community-based participatory action approach to this investigation by engaging Padres Contra el Cancer (PADRES), a local community-based advocacy organization for children with cancer and their families in Los Angeles. Over 70 percent of its program participants are Latino and Spanish-speaking. In May 2006, the Principal Investigator (Zebrack) convened an advisory board meeting to discuss plans for study design, procedure, and participant recruitment. The advisory board consisted of the PI, co-

investigators and research team, as well as cancer survivors, the mother of a brain tumor survivor, and a member of the board of directors from Padres Contra el Cancer.

PADRES program staff identified six YACS who were diagnosed with and treated for a pediatric malignancy prior to age 21, were off treatment for more than five years, and were between ages 18 and 39 at the time of study. Diversity in demographic and medical characteristics, such as age at diagnosis, gender, relationship status, and family type were taken into account in recruitment. Six YACS were recruited and asked to bring a family member. All procedures were approved by the University of Southern California (USC) IRB, and written informed consent for the research was obtained for all participants.

This project was implemented between September and December of 2006. A total of seven sessions were held every two weeks on Saturday mornings at Children's Hospital Los Angeles. The first meeting consisted of an orientation to the project. Staff distributed digital cameras to all participants, instructed them in their use, and then directed them to take a self-portrait somewhere in the hospital. At the end of Day 1, the study investigators asked participants to take photographs over the next two weeks that would capture "the impact of cancer on your family." All subsequent topics for future photographs were generated by the participants themselves through group discussions during each of the subsequent sessions.

Each of the next five sessions lasted two hours. Upon arrival, project staff greeted participants and conducted a 10-minute individual interview in which staff and participants looked at the photos that they had taken over the past two weeks, and selected one or two photos that they thought were most relevant to the specific theme of the day. In some instances, interviews were conducted in Spanish by Spanish-speaking staff. Participants provided captions for these photos, which staff recorded in a logbook. The interviewers asked the following questions to stimulate discussion of the photographs: What are you seeing in this picture?; What is happening in this picture?; How do you feel about this situation?; and why does this happen? (Wallerstein, 1987) After the individual interviews, participants were divided into a YACS group and a family member group and participated in an hour-long group discussion facilitated by the PI and a co-investigator. The YACS group was conducted in English; the family member group was conducted in both English and Spanish, as two participants were mono-lingual Spanish-speaking, three others spoke and comprehended Spanish, and one spoke English but not Spanish. All interviews and discussions were audio-taped and professionally transcribed verbatim. At the end of the hour, each group reached consensus on a theme for the next photo-documentation period.

Data Analysis

The audiotapes of all individual interviews and group discussions were transcribed in their original language, and then transcripts in Spanish were translated into English. The transcript texts were entered into Atlas-ti, qualitative data analysis software, to facilitate data management and analysis. In total, 14 hours of individual interviews and 10 hours of group discussions were included for analysis. The photos were used as visual representations of the participants' narratives, not as data in and of themselves.

We used the themes generated by participants as an organizing framework or template for data derived from the individual interviews and group sessions. Because the YACS group and the family group developed separate lists of themes, we analyzed the transcripts of the two groups separately. Also, because the participants were supposed to take photographs and have discussions about the group theme on each day, we analyzed the transcripts from each day separately. For example, all the transcripts of the YACS group from a specific day were analyzed to find the subthemes of that day. In detail, we conducted open-coding to condense the data into analyzable units by assigning shorter phrases or codes to segments of the

transcripts, ranging from a phrase to several paragraphs (Glaser & Strauss, 1967), and then we used the constant comparative method (Strauss & Corbin, 1990) to cluster the codes into new categories. Through this process, subthemes emerged under the template theme of the day. This procedure for finding subthemes under each template theme was repeated for each day and each group.

RESULTS

Participants

A demographic description of the sample is summarized in Table 1.

Themes of the YACS Group

I. Lost Childhood

Remembering hospital days: All the YACS had dreadful memories of cancer treatment. For example, Roberto described his hospital days as “being in jail.” On the other hand, most of the survivors shared the stories of breaking hospital rules and going outside, and they remembered these events as “having fun” and “feeling human again.”

Missed experiences: The YACS missed some childhood or adolescent experiences that were taken for granted by other kids, such as attending school, hanging out with classmates, going to school field trips, being out in the sunshine, and connecting with people outside the hospital. As Selena described it, she felt “left-out.” Some YACS believed that these missed experiences had had some influence on their current problems. For example, Antonio said that he was shy in social relationships, maybe because he had missed the opportunity to make friends and enjoy playing with other kids (see Figure 1, “The Childhood I Never Got to Experience”). Many YACS expressed the feelings of wanting to go back to their childhood and do what they had missed. Nostalgia toward the missed time was described by Sofia as a lingering “aroma” that she could “never quite catch or touch.”

Inside and outside: Most YACS spoke of feeling some gap between what they were inside and how they were perceived by other people. They attributed this phenomenon to their cancer experiences. Adileh expressed frustration: She kept being “judged” for not “acting [her] age” although she felt still “stuck in the past.” Selena said that she was treated as the baby of her family because her family was still worried about her health and that she “could never be a grown-up” to her family.

II. My Culture

United family: YACS talked about the importance of close family relationships in their culture. The family included not only parents and siblings, but also extended family members, such as grandparents, uncles, and aunts. Some survivors viewed their dead family members as their protectors. Many YACS had maintained close relationships with their relatives in their original countries before immigration: They regularly visited or communicated with them. All YACS viewed their family as an essential part of their cancer experience. For example, as Sofia described it, her family was her “strong soldiers and army” in her fight against cancer.

Healing food: Most of the survivors described food as an important element in their culture. According to Sofia, food is “a way of showing love.” Most YACS spoke of their memories of feeling at home by eating homemade food at the hospital. Some believed in the healing power of food and suggested that the hospital menu should be diversified to incorporate ethnic foods.

Religion: All YACS agreed that religion is part of their culture and that faith helped their families cope with cancer experiences by helping them stay in close ties. Many reported that cancer had strengthened their faith. Many YACS also described their survival as a religious miracle, believing that they had survived after having a dream about a saint (see Figure 2, “The Doctor’s Hand and God’s Miracle”) or a dead relative. Others reported receiving a caring and praying letter from an aunt, or having prayers from people.

Rituals: YACS often described cultural rituals and how cancer and treatment caused them to miss out on these important life experiences. For example, two Latina participants missed their Quinceañeras because of cancer. Adileh expressed frustration that she could not fast for Ramadan, an important ritual in her culture, because of her weak health.

Traditional remedies: Most YACS had positive opinions toward using traditional remedies. Mariana and Selena, who had gone through treatments at older ages than the other survivors, remembered having tried some remedies, such as gargling with wood salt, hot water, and baking powder for mouth sores; drinking teas for a stomachache; rubbing meat on the sore leg; and rubbing tomatoes or olive oil over the scalp to help hair grow back.

III. Health

Impact of cancer on the family: Most YACS felt guilty for the traumatic repercussions their cancer diagnosis had on the family. Sofia described the news of diagnosis as “a bucket of cold water” on the family, and Mariana told how much “chaos” cancer had brought to her family. Confusing medical information and decisions, the burdens of finance and insurance, and the lack of care for other siblings were listed as some examples of the impact on the family. Although most YACS noted that their families had sacrificed because of cancer, Selena particularly deplored the fact that the health of her parents had deteriorated because they could not take care of themselves while having to take care of her (see Figure 3, Untitled). Her photo depicts not her medications but those of her parents. Now 31 years old, Selena does not work, lives at home with her ailing parents, and rarely leaves home out of fear for her parents’ health and out of a sense of obligation she feels to care for them after all they did for her.

Lingering cancer: Most YACS reported currently having various health issues as direct or indirect results of cancer, such as diabetes, depression, high blood pressure, weight loss, loss of appetite, or bipolar disease. Although some YACS suffered from pain occasionally, they were holding back their pain from the family because they did not want to worry their family any more. Instead, they developed self-coping strategies. For example, Mariana kept journals to express her feelings that she did not want to share with her family. Those who said that they kept pain inside agreed on the need for confidants who were not family members.

Thinking about death and life: Having seen other children dying of cancer and having had their own near-death experiences, most YACS reported that they often thought about the existential issues of death and life. For example, Sofia was very specific, even to the extent that she decided exactly what her funeral would be like. Their responses to death were diverse: To Sofia, death became “common and a part of life.” To Selena, news of death was still shocking and hurtful. Some YACS reported that their cancer experiences had let them think about how to live a better life. As Sofia reflected,

I cheated death once...I guess it’s reminding me that you don’t have all the time in the world...sometimes I feel this desperate need to, like, go out and do something because time is wasting and death can catch up to you anytime.

IV. What Keeps Me Going/Sacrifices

Family: While most YACS emphasized the importance of the family in their coping with cancer, some expressed ambivalent feelings toward their families. For instance, Sofia described her dilemma between her family obligations and the desire for independence, saying, “I am torn between loyalty to family and wanting to be selfish... I want to plunge into life, but I cannot.” A few reported that their parents had overprotected them because of their childhood cancer and that this overprotection had deprived them of the opportunities to explore the world and had made them afraid of the world. Selena talked about a time when she felt obligated to choose her parents over her relationship with her boyfriend, and that she felt responsible for taking care of her parents because they had sacrificed for her:

When I wanted to move out with [her boyfriend], I started packing things up and I caught my mom crying and I asked her what’s wrong. She said, “You’re leaving me.”... I said, “You know what, I’m not going anywhere.” And I called [her boyfriend]... I’m not going anywhere. I’m staying home. So I just -- it’s just them. That’s my whole thing.

People: Although some survivors kept changing their mind about their future career goals, all of them wished to work in the helping professions such as nursing, social work, teaching, and medicine. Some explained that they wanted to work for other people because they had received tremendous help from other people, sometimes strangers, and they wanted to pay back. For example, Roberto was volunteering at the hospital “to testify as a survivor” to other cancer patients:

They [patients] just hate being under treatment and they want to give up. I just go and talk to them and tell them not to give up. Just to keep fighting. Give them a little moral support. Because they see that I’m the final product of all the suffering that they went through now. You got up once with the strength of everybody else around you... Now it is your turn.

Future: While most YACS stated that cancer had delayed or interfered with the achievement of their dreams, they still felt positively about their future. Mariana and Antonio had set their future goals and were diligently pursuing them to become a nurse and a teacher, whereas the others were not clear about what they would do in the future. Some questioned whether they had the financial resources needed to achieve their goals. Even those who were still searching for their future career seemed to be at ease with this uncertainty. For example, Roberto even described “the unknown” of the future as a motivator or hidden possibilities.

V. Who Am I?

Survivor: All YACS expressed that they felt a strong and positive sense of identity as survivors (see Figure 5, “Life”). Their experiences of surviving the disease led them to believe that they could also survive other life hardships, as described by Sofia:

At that time it was cancer. Um, there are just different things that I’m going to have to face...it will be tough, but I have, like, a strong history of not giving up easily. What doesn’t kill me makes me stronger.

I am More than what I look: Some YACS described the dual nature of their identity. For example, Selena said, “I am a fish in a tank,” referring to her calm and peaceful appearance in the outside and her inner struggle and chaos. Sofia also said that she shows only a small part of herself to others, but that the hidden and unrealized part might be the better.

Family and people: Most YACS reported that their identities were defined by their family. Antonio and Selena emphasized the importance of helping other people in forming their own identities.

Themes of the Family Member Group

I. How Cancer Affected Survivors' Hopes and Dreams

Sacrifices to cancer: All family members expressed that the YACS had suffered losses by missing a certain stage of life and that they had lost opportunities and dreams because of the side effects of cancer (see Figure 6, "Precious"). The side effects, including slow learning, memory problems, and a lack of self-motivation, were mentioned by the family members as stumbling blocks in the survivors' pursuit of their dreams. Adileh's mother felt "helpless and heartbroken" as she perceived her daughter's dreams of becoming a nurse as unrealistic and bound to "never" coming true. She added her concern about wanting to prevent disappointment or frustration that her daughter might experience by not achieving her dreams.

Still a kid: Most mothers were concerned that their surviving children were less developed than their peers in terms of social relationships and dependence on the family. Mothers in the group expressed feeling confused in their attempts to reconcile their wishes to see their children be independent and the reality that their children were not "normal" and still needed to be dependent on them.

Survivors' altruism: All family members were aware of the survivors' hope to give back by helping other people.

II. "Positive Impact of Cancer"

What helped: Most family members reported that having religion, faith, and hope had helped them through cancer experiences. Many believed that cancer survival was a religious miracle. Most of them expressed appreciating the support they received from other people, such as talking with other families going through cancer, receiving spiritual peace from church people, and receiving help from their extended family, social workers, and medical staff.

Give and take: All family members reported that they had received some positive benefits from cancer in return for their sacrifices. Most said that their family ties and religion had become stronger after cancer and that they realized that there were wonderful people in the world and there was always hope in any adverse situation. Some told that their personality or attitude had changed: Mariana's husband became more understanding; Selena's boyfriend became more patient; and Adileh's mother became brave and assertive (see Figure 7, "Strength and We Came Through").

III. Importance of Information

Information sources: The family members obtained information on services for the YACS from television, support groups, nurse practitioners, and health fairs. Some reported that they preferred personal contact to any online resources for obtaining such information even though they knew how to use the Internet.

Information needs: The mothers, in particular, wanted to know information on issues such as insurance, financial services such as free medical exams, and training for YACS on independence, socialization, and schooling. Adileh's mother most vocally described feelings of being frustrated and overwhelmed when trying to search for information, and she suggested one-stop information centers as a solution (see Figure 8, "Reaching out").

IV. Barriers to Self-Care

Caregiver's health: Most family members described their poor physical health conditions. Some examples of their health problems were fatigue, diabetes, high cholesterol, thyroid disorders, rheumatoid arthritis, and high blood pressure. Some believed that these physical health problems were the “manifestation” or “explosion” of their psychological problems, such as anger; feeling like an “emotional zombie” with the “never-ending” battle against cancer; “empty feelings”; the fear of another cancer; and the uncertainty about the future. Many reported wanting to “cry”, “scream”, and “take out what they had inside.” They were “swallowing all the issues inside” to look strong to the family. They believed that if they showed weakness to their family then family members would feel insecure.

Lack of self-care: Most family members spoke of not doing anything to take care of themselves. Mariana's husband depicted this lack of self-care as “I am always on the backburner.” Similarly, Adileh's mother said, “I am the last on the to-do list or do not exist.” Only Antonio's mother mentioned doing some self-care, such as taking vitamins and eating healthy. Some explained that they could not take care of themselves because they simply did not have such time. Mariana's husband and Adileh's mother felt “selfish” to think about themselves because they were supposed to “be there just as a helping hand” for the survivors, not for themselves. Roberto's mother expressed her belief that “If my family is fine, I will be fine.” Most family members said that what they did to bear their physical and mental health problems was to try to be grateful for their cancer survival and to be positive. Mariana's husband called his efforts to focus on the positives “tricking his mind.” He continued that sometimes when such efforts did not work, he would feel “angry, questionable toward my faith, overwhelmed, and helpless.” Most emphasized the urgent need for self-care because they might not be able to “take the burden too long” and would “explode” someday soon. Many wished to enjoy time for their own with music, gardening, dancing, and exercise if they could afford to.

Other family issues: While most family members agreed that cancer had affected every member in the family, the mothers, in particular, were most concerned about the effects on the YACS's siblings. All mothers felt guilty that they had “neglected” their other children, often leaving them with extended family members during prolonged treatment. These mothers described how siblings made a lot of sacrifices. For example, Antonio's mother reported that Antonio's sister felt limited in doing certain things because she “did not want to offend him” by doing something that he could not do because of the side effects of cancer. Some mothers were worried about estranged sibling relationships. Some reported that siblings complained about their parents' treating the survivors different from themselves. The mothers talked about the coping problems of their husbands, as well. Sofia's mother said that her husband had depended on alcohol to cope with their child's cancer, and Roberto's mother stated that her husband coped by never mentioning cancer and that he cried whenever he was reminded of her cancer.

V. What We Learned and What We Can Do

Therapeutic effects of the project: Most reported that coming to this project biweekly was a “time-off” for them. Some appreciated the opportunities to “vent” their feelings in the interviews and discussions. To many, this was their first time talking about cancer since treatment had ended. Antonio's mother appreciated that she and her son were finally able to talk about cancer as a result of participating in the project together. Roberto's mother mentioned that Photovoice would be good to elicit stories from cancer survivors' fathers because the fathers never express their experiences with cancer in the family.

What we can do: Some wanted to educate the public about cancer that this disease “can happen to anybody” and “is not contagious.” Most also wanted to give hope and faith to other cancer-affected families and share information with others based on their experiences (see Figure 9, “Fully aware”).

DISCUSSION

This study can be differentiated from others in at least three elements. First, it was a participant-driven study. Except for the first theme offered by the researchers (“How has cancer affected your family?”), participants defined all subsequent topics around which they took photographs. The analysis was conducted with participant-derived themes as an organizing framework for the context. Second, this study was family-based, including both survivors and their family members. The rationale for this participant-driven and family-based framework was based on the belief that the cancer survivors and their families were the “experts” of their experiences and problems. Third, an innovative participatory research method, Photovoice, was used as a way of deriving participant-driven themes from members of population subgroups that are often excluded from research that utilizes conventional survey methods.

These unique approaches and methodology resulted in some novel findings. First, we found that the main themes of the YACS’ cancer survivorship experiences were closely related to developmental milestones. Arnett states that there are five main characteristics of Emerging Adulthood (EA): (1) *identity exploration*, (2) *experimentalism/possibilities*, (3) *negativity/instability*, (4) *being self-focused*, and (5) *feeling in-between* (Arnett, 1998). Experiences of the YACS in this study reflected both protective elements as well as risk factors in each of these areas. Cancer was a main element in defining the self-identities of the YACS, and played a role in survivors’ *identity exploration*; for example, building positive images of themselves as survivors in a battle with cancer. Cancer also seemed to interfere with YACS’s *experimentalism* and engagement in new *possibilities*. According to Arnett (1998), emerging adults actively experiment with different opportunities in social relationships, jobs, and romantic relationships. However, the YACS had little to say about their social or romantic relationships, and many of them reported not being able to explore the world as much as they wanted because of the side effects of cancer, their obligations to the family, or their parents’ overprotection. Cancer seemed to reduce *instability and negativity* that usually characterizes this age group. YACS acknowledged that they were generally at ease with the uncertainties of their life. Parry (2003) suggests that survivors’ capacity for tolerating uncertainties of life during young adulthood might be a result of their previous experiences of dealing with the tremendous uncertainty and life threat associated with cancer.

YACS appeared to experience detriments in *being self-focused*, defined as having more independence, responsibility, and freedom than in adolescence (Arnett, 1998). They reported being overly dependent on their families, which in some cases precluded time with friends. In other instances, parents were still in charge of taking care of their medical services and seeking relevant information. In terms of *feeling in-between*, YACS’s comments often reflected being caught between feeling obligated to others and desirous of moving on and forward in the world. Having had to miss “normal” teenage life experiences because of cancer compounded the in-between feelings.

Of particular note, culture was an overarching theme affecting many aspects of the cancer survivorship among these YACS participants. Discussions of family and religion were explicitly identified as important parts of their culture and lives. Such classification contrasts with prior conceptualizations of family as being representative of a social domain and religion being representative and distinct to a spiritual domain (Ferrell, Hassey, & Grant, 1995). In this

patient-driven study comprised of representatives from underserved and underrepresented sub-populations, new conceptualizations of culture in the context of cancer survivorship emerged.

Third, this study listened to both the YACS group and the family group to draw triangulated pictures of cancer survivorship, and this triangulation produced several meaningful findings. The family group corroborated and elaborated on many of the themes that the YACS group discussed. For example, themes related to social relationships rarely occurred in the discussions among the YACS, whereas mothers were explicitly concerned about the survivors' lack of social relationships. By having both groups in the study, insufficient information in one group was complemented by the other group, exposing some issues that would have otherwise hidden to the surface. The findings on the lack of social relationships among YACS were consistent with Balling (2002)'s study. The family-based approach also found the lack of communication about cancer within these families. Both survivors and family members reported keeping their problems inside despite or because of close family ties. They were trying to protect each other from worries by hiding their pain.

Finally, Photovoice offered participants an opportunity to dialogue about cancer in ways they never have. Many participants reported that they had never really talked about cancer in their family before participating in this study and that taking and looking at pictures together smoothly led to cancer talks in the family. Also, photographs seemed to facilitate reflection, sharing, and dialogue in the research. Some participants said that "photos were a good way of talking" and "the more I see it [the photo], the more I think." As observed in other investigations utilizing Photovoice, photographs encouraged participants to tell their own stories (Hagedorn, 1994), provided a unique way of communication (Clark-Ibanez, 2004), and thus elicited rich information (Collier, 1979). The participants also seemed to have obtained therapeutic and empowering effects from the study participation. Some family members said that participating in the Photovoice project was like "getting support from support groups." They clearly showed intentions to act, which was categorized by Carlson, Engebretson, and Chamberlain (2006) as the most advanced stage of critical consciousness (Freire, 1970, 2000). They were willing to help and share information with other people, and wanted to educate the general public to destigmatize cancer and give hope and faith to patients and their families. In fact, when invited by a local children's hospital, two of the YACS participants presented their photographs from this study and their cancer experiences in front of the medical staff.

LIMITATIONS

There are several limitations to this study that deserve mentioning. First, the participants might not represent the broader population of YACS and their families as they were relatively healthy volunteers and actively involved in the local community-based agency (PADRES)'s activities. Second, because of the heterogeneous demographic and medical characteristics in the small sample, association of these characteristics with the participants' perspectives on the impact of cancer could not be examined. However, despite the diverse sample, this study found a great deal of commonality in the cancer survivorship experiences above and beyond the individual differences. Third, any causal relationships could not be established because pre-cancer data and/or comparison groups were not available. For example, it could not be known whether the survivors' optimism toward the future was attributable to their cancer experiences, the developmental characteristics of young adulthood, or personality traits.

We employed several strategies to enhance the rigor of qualitative analysis. The process of analyzing data was monitored through the use of memos, a detailed recording of the analytic process to ensure future reproducibility (Devers, 1999; Miles & Huberman, 1994; Schwandt & Halpern, 1988). While generalizability is limited by small sample size, prolonged engagement and triangulation contributed to credibility and utility of the research. As the

project lasted through seven sessions over three months, prolonged engagement was established, thereby ameliorating some of the effects of reactivity and respondent bias (Padgett, 1998). Triangulation was practiced in two ways: 1) by using the data from individual interviews as well as group discussions; and 2) by using the data from the survivors and from their family members.

RESEARCH AND CLINICAL IMPLICATIONS

Results of this work include some concrete suggestions for the improvement of care and the institutional environment. For example, the participants made several suggestions such as diversifying the hospital menu to incorporate ethnic foods; accepting traditional remedies for easing side effects from cancer treatment; providing help to fathers and including them in research; and developing one-stop information centers for cancer-affected families.

Findings also suggest a need for YACS-targeted guidance and training on (re)engaging in social relationships and achieving independence, and career or gainful employment. Both YACS and family members need instrumental and emotional support from outside of the family. YACS might experience different levels of maturity in different domains: They seem to be more mature in mental and existential domains than in social domains. Research and practice efforts should be made in the ways that YACS can explore social relationships and activities.

Second, professional help in regards to parenting concerns and information on YACS' independence is needed. Mothers of cancer survivors might suffer from parenting confusion about how to treat the survivors and other children. As expressed by one mother, they might constantly ask themselves, "Am I being a good mother?" Family-centered interventions can be helpful to address differences in YACS' perceptions of their own capabilities and their parents' perceptions and resultant over-protection. It seems clear that parents' worries are not necessarily connected to their child's worries. Parents' over-protection and worry is perhaps a barrier to their child's achieving hopes and dreams. What seems less known is how survivors can navigate the chasm between their hopes and dreams and what is truly a 'realistic' expectation given their physical, mental and cognitive status/effects from cancer.

Third, family dynamics and family communication need special attention with culturally-sensitive eyes. *Familismo* has been studied as a core value associated with quality of life among Latino families (Zinn, 1982). In our study, where the majority of the participants were Latino descendents, family was found to play such a central supportive role in their cancer survivorship. However, we should not ignore the clear voice both from the YACS and their family members: They were suffering inside under the good name of protecting each other and keeping their family-oriented culture. It is risky to assume that the families with rich internal support could self-sufficiently resolve all the issues from cancer. The participants in this study reported urgent needs for "listeners" and emotional supporters who were not family members. Practitioners should focus on developing effective ways to let cancer-affected families release their stress and communicate their problems and, at the same time, to respect their cultural wish to protect the family equilibrium. Future research should examine not only positive factors of *familismo*, but also its negative factors in cancer survivorship. Programs and interventions are needed for the minority families, especially from family-oriented cultures. The family-based approach also revealed that the family members were not aware of the positive impact of cancer on the survivors. According to the study by Zebrack (2002), mothers' worries were more related to their own perceptions of their children's worries than to the objective physical consequences of their child's illness. If family members recognize that their surviving children cope with cancer well and even obtain positive benefits from cancer, they might feel less worried.

Fourth, the mental and physical state of the family members was severe, and the urgent need of care for the family members emerged as an important issue. Although the families in this study had experienced cancer in the family 8–23 years ago, what they reported about their physical and mental strains was alarmingly similar to what the family members of cancer patients under active treatment reported in the book by Chesler and Barbarin (1987). If the family members had “piled up” (Hill, 1949) stress for such a long time since cancer diagnosis, it was understandable why they reported that they were about to “explode” sometime soon. These families might desperately need help and support from outside of the family.

CONCLUSION

This study sheds light on the complex picture of young adult cancer survivorship, and future research should focus on studying the whole person struggling with the duality of the cancer survivorship paradox. Opposed to the trend in the existing literature of focusing on either positive or negative aspects of survivorship, this study found both aspects within the same participants. As Calhoun and Tedeschi (1999) recommended, clinicians must be tuned to the positive sides discovered by cancer-affected families and encourage them. At the same time, it should be kept in mind that even seemingly-resilient families might need external help to deal with the negative impact of cancer which is likely to come in pair with the positive.

One of the original purposes for initiating this project was to engage a community-based service organization and its constituency in an effort to improve institutional health care for families of children with cancer. In establishing a relationship with these 12 photovoice participants and carrying out this project, we realized that the participants did not share our ambition. For them, they participated because doing so was of personal value and they were not in it for anything other than to partake in a shared experience with others who shared similar interest and concern. In “being where the client is at,” we adjusted our expectations such that our goal became providing the best possible experience for these 12 individuals and understanding their experiences. Thus, a meaningful contribution of this study might be in our opportunities as social work researchers and clinicians to display self-portraits of childhood cancer survivors and their families within own life context and composition. As is often the case in clinical social work, we may never know the long-term impact we have on our clients. But we are often left with poignant words and memories of those for whom we come to care deeply. And, we continue to try to understand who they are and listen to their stories: As Sofia so poignantly wrote,

I am from weeklong wakes and overnight vigils. Mother’s hand held my limp fingers through the railing of the hospital bed... I am from doctor’s hands and God’s miracles. I am from strangers’ prayers and your embraces.

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FIGURE 1.
“The Childhood I Never Got to Experience”

FIGURE 2.
“The Doctor’s Hand and God’s Miracle”

FIGURE 3.
Untitled

FIGURE 4.
Untitled

FIGURE 5.
“Life”

FIGURE 6.
“Precious”

FIGURE 7.
"Strength and We Came Through"

FIGURE 8.
“Reaching out”

FIGURE 9.
“Fully aware”

Table 1

Demographic and Medical Information on the Participants

Pseudonyms	Gender	Cancer type	Ethnicity	Age at diagnosis	Age at study	Family members (if interviewed in Spanish)
Sofia	Female	ALL	Mexican	5	21	Mother (Spanish)
Roberto	Male	Germinoma brain tumor	Hispanic	14	21	Mother (Spanish)
Mariana	Female	ALL	Hispanic-Indian	13	30	Husband
Selena	Female	Osteosarcoma	Mexican	17	33	Boy friend
Antonio	Male	ALL	Hispanic	3	26	Mother (Spanish)
Adieh	Female	Brain tumor	Persian American	12	20	Mother

Note. ALL are the initials of Acute Lymphoblastic Leukemia

Table 2

Themes and Subthemes of YACS and Family groups

	YACS Group	Family Group
1 st Themes	Los Childhood	How cancer affected survivors' hopes and dreams
	Remembering hospital days	Sacrifices to cancer
	Missed experiences	Still a kid
	Inside and outside	Survivors' altruism
2 nd Themes	My culture	Positive impact of cancer
	United family	What helped
	Healing food	Give and take
	Religion	
	Rituals	
	Traditional remedies	
3 rd Themes	Health	Importance of information
	Impact of cancer on the family	Information sources
	Lingering cancer	Information needs
	Thinking about death and life	
4 th Themes	What keeps me going/sacrifices	Barriers to self-care
	Family	Caregiver's health
	People	Lack of self-care
	Future	Other family issues
5 th Themes	Who am I?	What we learned and what we can do
	Survivor	Therapeutic effects of the project
	More than what I look	What we can do
	Family	
	People	