

Chapter 8

Resilience and Pediatric Cancer Survivorship in Cultural Context

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Having cancer is officially recognized as a potential trauma threat in the *Diagnostic Statistical Manual of Mental Disorders* (5th ed.; *DSM-5*; American Psychiatric Association, 2013). However, there are countless triumphant individuals, including children, who have survived, and even thrived, after cancer. An estimated 175,000 children under the age of 15 are diagnosed with cancer each year worldwide. The overall 5-year survival rate for pediatric cancer is around 5–10% in Bangladesh, the Philippines, Senegal, Tanzania, and Vietnam; 30% in Morocco; 40–60% in Egypt, Honduras, and Venezuela; and 81% in the USA (American Cancer Society, 2014). As of 2010, approximately 380,000 survivors affected by childhood and adolescent cancer live in the USA.

Despite the increasing global childhood cancer survivor population, there are surprisingly few cross-cultural studies on resilience and childhood cancer survivorship. Although studies of cancer survivors have been conducted in different countries, truly cross-cultural comparisons, encompassing values, ideas, and norms (Gunnestad, 2006), have not adequately been attempted (Gray, Szulczewski, Regan, Williams, & Pai, 2014). Considering that illness experiences are socially and culturally affected and constructed (Kleinman, Eisenberg, & Good, 1978), the cultural aspects of cancer survivorship warrant research and practice attention. Although cultural discourses surrounding “strength,” “resilience,” and “survivorship” are becoming increasingly developed, much global research in pediatric psychoncology is still based on biomedical models of disease—a deficit model that primarily documents the negative psychosocial aspects of cancer (Parry & Chesler, 2005). With globalization occurring at a dramatic speed and scope, research must

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anticipate and accommodate the realities of diverse populations of survivors from different cultural backgrounds living together. Understanding resilience in pediatric populations in multicultural contexts is essential for promoting research and developing adequate and appropriate services and psychosocial interventions.

Fostering resilience is an important part of enabling children with cancer to overcome traumatic illness, adjust to life after cancer, and thrive into adulthood (Wu et al., 2015). As we will review in this chapter, strategies to promote resilience vary across different cultural contexts, especially because illness and disease is perceived and interpreted differently across cultures. In the field of social work, it is essential to understand and help people in their own environment, at the individual, family, community, and cultural levels (Mattaini, 1995). Social workers provide services by using the “person-in-environment” paradigm and assessing the patient and family’s particular resources, strengths, and limitations (Glajchen, Blum, & Calder, 1995). We will review the findings of our recent cross-cultural cancer survivorship study in order to identify potential cultural factors that affect resilience in pediatric cancer survivorship.

The Korean Childhood Cancer Survivorship Study

The Korean Childhood Cancer Survivorship Study (KCCSS) was one of the first to examine the positive and negative psychosocial impacts of childhood cancer on adolescent and young adult survivors in Korea. Participants were childhood cancer survivors between 15 and 39 years old who had completed all cancer treatment (e.g., chemotherapy, radiation therapy, and bone marrow transplants) at the time of the study. Participants were recruited through online and off-line announcements of the study at advocacy foundations and support groups for childhood cancer survivors and their families throughout Korea. Because this population can be difficult to reach once medical treatment is complete, due to stigma attached to cancer in Korean culture, snowballing method was additionally used to recruit participants.

A combination of qualitative and quantitative methods was employed in the study. Qualitative hour-long interviews with 31 individual survivors were conducted in Korean by phone or in person by two researchers knowledgeable about pediatric cancer survivorship. The interview included discussion of the survivors’ past and present cancer-related experiences, the positive and negative impacts of cancer on their quality of life, the roles of their families, their health beliefs, and suggestions for services.

Structured questionnaires were also mailed or emailed to potential participants, and 225 childhood cancer survivors who met our study criteria responded. The survey questionnaires included questions on psychological distress, post-traumatic stress disorder (PTSD), posttraumatic growth (PTG), stigma towards cancer survivors, spirituality, social support availability, self-esteem, coping strategies, optimism, communication about cancer experiences, perceived functioning, sociodemographic variables (e.g., age, gender, marital status, education, and

employment), and cancer-related variables (type of cancer, cancer recurrence, age at diagnosis, and time since diagnosis). Most of the variables were measured using existing scales, including the Brief Symptom Inventory–18 (BSI-18; Derogatis, 2000) for psychological distress; the Medical Outcomes Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991) for perceived availability of social support; the Posttraumatic Stress Diagnostic Scale (PDS; Foa, Cashman, Jaycox, & Perry, 1997) for PTSD; the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) for PTG; the Life Orientation Test (LOT; Scheier, Carver, & Bridges, 1994) for optimism; the Medical Outcomes Study Short Form-8 (SF-8; Ware, Kosinski, Dewey, & Gandek, 2001) for perceived functioning; the Global Self-Esteem Scale (Rosenberg, 1965) for self-esteem; and the Daily Spiritual Experiences Scale (Underwood & Teresi, 2002) for spirituality. Some measurements were tailored from the original version for use with childhood cancer survivors. For example, communication was measured by using a single item of talking about stressful events derived from a previous study (e.g., Murray, Lamnin, & Carver, 1989); perceived public stigma was measured using a combination of subscales from the Social Impact Scale (Fife & Wright, 2000) and the Devaluation-Discrimination Scale (Link, Cullen, Struening, Shorout, & Dohrenwend, 1989); and coping strategies were measured using items modified from the Brief COPE (Carver, 1997). As described in Kim and Yi (2013) and Yi and Kim (2014), the English version of the questionnaire was translated following rigorous translation procedures, and modified based on cultural considerations by the authors who are bilingual and bicultural in English and Korean.

Findings from the qualitative and quantitative data were used to develop psychosocial programs and inform future research with this population. Several manuscripts on the study findings have published in the fields of social work (Kim, Yi, & Kim, 2014), nursing (Kim & Yi, 2012, 2013; Yi, Kim, & Sang, 2016; Yi, Kim, & Tian, 2014), and psychology (Yi & Kim, 2014). In what follows, we introduce our Culturally Directed Model of Resilience Work. We highlight four culturally mediated processes from our data—social connections, confronting cancer, coping, and growth—that we believe are relevant to resilience in this model.

The Culturally Directed Model of Resilience Work

We propose a Culturally Directed Model of Resilience Work, which is informed by our findings and current literature in pediatric cancer survivorship across diverse cultural contexts. Four important points must be emphasized: First, in this model resilience is conceptualized as a dynamic process in which adaptation depends on interaction between personal and environmental factors (Margalit, 2003; Velichkovsky, 2009). Second, because what constitutes “risk” and “doing well” is culturally variable, the process of resilience as a whole is influenced by culture. Third, individuals are active agents in the process of resilience. When one faces a major life challenge, protective and risk factors interact to help or hinder the person

in adjusting to the challenge. This is not a passive process; rather, the individual actively participates and responds to the situation and culture contributes to the individual's response. We call this process "resilience work," meaning that effort is put forth in multiple social domains to create a resilient responses. Fourth, resilience experiences accumulate and become part of the person. During and after one has experienced a major stressor, one may find growth in his or her identity, coping skills, and social capital, and become a better, more resilient person (Garland et al., 2010; Velichkovsky, 2009). When confronting the next life challenge, he or she deals with the situation with up-scaled sets of protective factors enhanced by the previous stress experience.

In the following sections, we will examine four factors affecting the Culturally Directed Model of Resilience Work: Social Connections; Confronting Cancer; Coping; and Growth. Our discussion will be based on insights from the KCCSS findings and current literature in pediatric cancer survivorship.

Social Connections

Family, friends, teachers, neighbors, health care staff, and other significant people in a child's social ecology all have the ability to help them overcome adverse situations. Family members, as immediate caregivers, play a particularly critical role in helping children cope with cancer. Resilience is clearly not only the result of the individual's positive behavioral patterns and functional competencies; rather, it is the combined effect of the family and individual's psychosocial health and well-being (McCubbin & McCubbin, 1996). Likely due to the importance of the family's role in pediatric cancer survivorship, most of the studies on resilience in this field examine the family members' social resources rather than those of the cancer-affected child (Kawakami et al., 2013; Rosenberg, Baker, Syrjala, Back, & Wolfe, 2013). A recent review article by Gray et al. (2014) found that out of 72 articles published between 1980 and 2012 on cultural issues surrounding children with pediatric cancer or their families, only eight articles included the perspective of patient informants themselves. For example, Brody and Simmons (2007) explored the resources that help fathers adapt to life after their child's diagnosis. They found that support from extended family, the church, and health care professionals were necessary for fathers to remain positive during their child's illness. There is no doubt that family members' psychosocial health and well-being are important—children with cancer who reported higher family function were more resilient than their counterparts (Kim & Yoo, 2010). Nonetheless, more empirical studies on social resources directly connected to the *child* need to be conducted. In the following passages we suggest several cultural factors that should be considered while exploring this topic.

The degree and nature of care the family provides is affected by a variety of cultural differences including boundaries, roles, and dynamics. For instance, involvement of extended family members such as grandparents, aunts, and uncles in the

child's care differs by ethnic groups. Yi and Zebrack (2010) found that, for Mexican and Hispanic children with cancer, extended family systems were an essential part of the coping process. In Korea, where cancer is extremely stigmatized, the family may struggle with communicating the needs of their children and asking for social support outside of the family (Yi, 2009). Further, in some cultures gender and ethnicity may determine the psychological support that is available within the family (Yi, 2009). For example, female cancer survivors reported significantly less support from friends and higher negative affect compared to males; and ethnic minorities such as African Americans, Asians, and Hispanics reported lower friend support than whites, in Wesley, Zelikovsky, and Schwartz's (2013) study on adolescents with cancer in the USA. Attention should be paid to these factors when attempting to understand social connections in pediatric cancer survivorship.

The parent-child relationship is vital in every child's development and even more imperative for a child going through an adverse circumstance like cancer (Orbuch, Parry, Chesler, Fritz, & Repetto, 2005). Again, this relationship varies cross culturally. Parents provide many different kinds of support for their child, including instrumental, informational, and emotional support. For instance, in both Native American and African cultures relationships are oriented towards sharing, networking, and cooperation and these in turn become positive factors in fostering resilience. Among Latinos, family relationships and parental influence have a strong role in fostering resilience and encouraging youths to stay away from high-risk behavior (Gunnestad, 2006). One of the relevant roles that parents can play to promote the child's resilience is modeling through words and actions. Phillips and Jones (2014) provided an example of a Latina mother whose words (e.g., "You can get through this," "You're strong," "We're gonna take care of you," and "We're gonna help you.") gave her child emotional support to cope with cancer. By contrast, in India parents are discouraged from informing children about their disease and including them in the decision-making process of treatment (Seth, 2010). This can delay the treatment process and the receipt of counseling services post treatment (Seth, 2010). For more on the role parents play in promoting children's adjustment to chronic illness, see Hoehn et al., this volume.

Since they may miss large parts of school education and activities, cancer-affected children are challenged with achieving social development milestones (Brown, Bolen, Brinnkman, Carreira, & Cole, 2011). Missed experiences in school and the associated lack of development and skills in making friends contributed to social isolation of childhood cancer survivors in many studies (e.g., McLoone, Wakefield, & Cohn, 2013; Yi & Zebrack, 2010). In the KCCSS, it was found that although children were interested in going back to school, they hesitated due to a lack of confidence in school activities, and had anxiety about relationships with peers (Yi, Kim, Hong, & Akter, 2016). The participants who reported being bullied by peers were isolated; in contrast, some of the participants received assistance from their peers and for them school reentry was easier. Unfortunately, some of the participants also had a difficult time with teachers who were unwilling to understand their school adjustment problems. Without support from their peers and teachers the participants felt isolated, which affected their coping process.

Studies conducted in western countries produced similar findings. McLoone et al. (2013) report that negative social reactions are the most challenging aspect for successful school reentry for children with cancer. Specifically, peer teasing and rejection were identified as the major barriers (Chekryn, Deegan, & Reid, 1987; Fraser, 2003; McLoone et al., 2013). Investigating negative cultural perceptions about cancer and the accompanying difficulty of school reentry is especially important since negative social environment is often a better indicator of posttraumatic stress symptomatology than lack of positive support (Ullman & Filipas, 2001; Zoellner & Maercker, 2006). For more on the transition to adolescence in chronically ill children, see Lennon et al., this volume.

Finally, in the KCCSS (Kim & Yi, 2012), pediatric cancer survivors expressed a strong need to connect with other survivors and wanted to be involved in mentor-mentee relationships, especially with cancer survivors who went on to find success in their careers and other areas of life. These “veteran” survivors can act as role models and also provide hope for stressed parents (Parry & Chesler, 2005).

Confronting Cancer

How and when a child learns of their illness will influence their ability to be resilient. Disclosure of diagnosis varies greatly by culture. Gray and colleagues’ review paper (2014) stated that parents in some countries (i.e., Taiwan, China, and Japan) prefer not to inform the child of his or her illness. Perhaps the parents are reluctant to discuss such a difficult topic, struggle with how much information should be provided, or worry about the stigmatizing effects of illness on the child and the family. By contrast, in western cultures the child’s autonomy is valued (Seth, 2010), and medical professionals generally believe that disclosure of diagnosis helps the child deal with treatment and increases their participation in care.

Gray et al. (2014) also point out that disclosure of diagnosis helps children seek social support; however cultural influence may vary in this aspect too. Mayer et al.’s (2005) cross-cultural study reports that US physicians preferred informing school personnel and classmates about the health status of children, while Japanese physicians did not. Indeed in Japan it is common for cancer-affected individuals to undergo extended hospitalization in order to avoid social stigma until the effects of treatment have completely disappeared.

Although Wong and Chan (2006) suggested that the practice of not disclosing diagnosis to the child has been decreasing in China, we found in the KCCSS that a majority of the Korean qualitative interview participants were not told of their diagnosis at the time of treatment (Yi, Kim, Grahmann, & Wu, 2016). Without communication, opportunities for modeling resilience and obtaining social support might be missed. It is important to note, however, that the impact of disclosure and communication about cancer experiences can vary across social networks even within the same cultural context. In a follow-up study to the KCCSS conducted with 68 childhood cancer survivors in Korea, it was found that in addition to

individual-level factors, some network-level factors (i.e., the relationships the survivors held and the nature of social support they were engaged in) impacted their discussion about diagnosis and cancer experiences (Kim, Yi, Prince, Nagelhout, & Wu, 2016).

The Self-Sustaining Process Model (Hinds & Martin, 1998) posits that adolescents experiencing cancer go through four phases: *cognitive discomfort*, *distraction*, *cognitive comfort*, and *personal competence*. Working through these four steps enables cancer survivors to become competent and resilient. Ishibashi et al. (2010) found that adolescents who were directly informed of their cancer experienced resilience, successfully moving through each of the four phases of the model. Those who learned of their diagnoses indirectly did not experience a complete passage through the phases.

Although parents and other caretakers may have good intentions when they don't tell children of a cancer diagnosis (perhaps wanting to protect the child from seemingly unnecessary pain and suffering), these findings indicate that doing so might actually hinder the child from successfully confronting the reality of the situation and ultimately being able to grow from the experience (Hatano, Yamada, & Fukui, 2011; Yin & Twinn, 2004). Even worse, the child often still indirectly learns (such as by overhearing a discussion) what is happening, regardless of the parents' desire to keep it a secret. A majority of the survivors interviewed in the KCCSS reported that they sensed something was wrong even though they did not receive any information about their diagnosis. Consequently, many resorted to searching online or worrying alone to try to fill the gap between the lack of information and the sensed reality (Yi et al., 2016a). Indirectly or incorrectly learning about the cancer diagnosis seems to be common in cultures such as Korea where cancer is a taboo with negative public perception. Secrecy can produce a preoccupation with the matter even after the truth is disclosed (Lane & Wegner, 1995). Stress resulting from the secrecy surrounding cancer among pediatric cancer survivors is a fruitful area of future research.

About 40% of the KCCSS participants expressed agonizing over the question "Why did I get cancer?" Some survivors attributed their cancer to internal factors, such as being bad, or to bad eating habits, stress, characteristics, heredity, genetics, or to magical thinking (e.g., "I thought of negative things, so I got cancer") while others attributed their cancer to an external cause, such as bad luck, a medical condition, or the environment (Yi et al., 2016a). The common theme in the questioning was that the survivors wanted to find out why they were suffering and to come to terms with the situation by settling on answers that seemed reasonable to them. Kleinman (1988) suggests that sickness raises two fundamental questions for the sufferer: "Why me?" and "What can be done?" Humans make sense out of chaos by repeating and pondering questions, creating theories, and attributing causes to situations (Kelley & Michela, 1980). Surprisingly little research has been done on how the cancer-affected child deals with such questions, especially in those cultures where cancer talk is secretive. Illness attribution studies have been mostly conducted on parents' attribution of cancer causes (Cimete & Kuguoglu, 2006), with few on the *patient's* causal attribution. Caretakers might be able to more directly

confront cancer together with their child if they gain a better understanding of the process of understanding the illness.

In Yuen, Ho, and Chan's (2014) study, hope and posttraumatic growth was mediated by cancer-related rumination among young adult childhood cancer survivors. Intervention studies are warranted to discover how to best balance the stress of confronting hard questions with the comfort of making sense. Conversely, if meaning is not successfully made, the patient may end up suppressing their feelings of dissonance, which may harm them more in the long run. A study of the victims of the Perth flood revealed that thought suppression was one of the best predictors of symptom severity, even after statistically controlling for the emotional intensity of the specific circumstances (Morgan, Matthews, & Winton, 1995). The possibility that thought suppression contributes to the persistence of PTSD was also suggested by a prospective longitudinal study of patients injured in motor vehicle accidents (Ehlers, Mayou, & Bryant, 1998). How thought suppression occurs and works in different cultures is not known and warrants future research. With this caveat, pediatric cancer survivors should be encouraged to confront cancer and should be supported by parents, caretakers, and other social connections to make meaning from their experiences.

About 20% of the participants in the KCCSS were classified as psychologically distressed (Kim & Yi, 2013), a higher prevalence compared with findings from the Childhood Cancer Survivors Studies in the USA. Although further studies on the predictors of such distress are needed, we theorize that the cultural norm of suppressing and tabooing cancer talk may play a role.

Coping

Culture also influences the way individuals manage life challenges and adjust to new circumstances. A recent review by Gray et al. (2014) describes how adolescent and young adult Latino patients coped with their cancer diagnosis by employing positive attitude, humor, and meaning finding (Jones et al., 2010). While European American and Latino American mothers of children recently diagnosed with cancer shared some coping strategies (e.g., gathering information, seeking professional help, participating in activities, problem solving, positive thinking, orienting in the present, reframing, avoiding, and practicing religion), they also coped in culturally distinct ways. In Johns' study (2009), European American mothers used compromise such as negotiating with the medical team for their children's treatment plans while Latina American mothers normalized the situation and kept perspective. Other studies indicate that Iranian, Latino, and Chinese families incorporated information-seeking strategies as a way of regaining a sense of control (Aguilar-Vafaie, 2008; Johns et al., 2009; Wills, 1999), while South African families tended not to because they perceived receiving information about their illness an unhelpful additional stressor (Jithoo, 2010). People tend to choose the coping strategies that are compatible with the specific cultural settings that they belong to.

Incorporating coping strategies is part of the “resilience work” concept that we propose—that individuals consciously put efforts into making resilient choices and achieving resilient outcomes. From that perspective, it is prudent to ascertain why cancer patients and survivors in certain cultures tend to use particular strategies to deal with stress. In the current literature on children with cancer, research is focused on what kinds of coping strategies are widely used (Li, Chung, Ho, Chiu, & Lopez, 2011) and what outcomes, especially positive or negative, they seem to produce (Aldridge & Roesch, 2007; Castellano et al., 2013; Park, Edmondson, Fenster, & Blank, 2008). Despite knowing that cultural influences play a significant role in resilience, understanding why pediatric cancer survivors use specific types of coping strategies and whether such strategies are culturally bound and resilience-promoting has not been fully explored.

The same coping strategy might be both adaptive and maladaptive in different contexts (Gray et al., 2014). Buse, Burker, and Bernacchio (2013) explored cultural variations of coping strategies (including locus of control, emotional regulation, somatization, self-enhancement, dissociation, family and community support, and spirituality such as rituals and ceremonies) in resilience as a response to traumatic experience. They found that although perceived internal locus of control is considered a resilient response in individualistic cultures, it may not apply to individuals from Japanese and Latino cultures where passive resignation to adverse circumstances and acceptance of one’s fate is valued.

In the KCCSS, childhood cancer survivors in Korea used diverse coping strategies, such as *Approach Coping*, representing problem-solving activities directed at the source of the stress; *Social Coping*, representing behaviors directed toward relationships with others; and *Avoidant Coping*, representing behaviors that orient the focus away from the problem (Yi, & Kim, 2016). Unlike in Western cultures, where humor may be used to avoid the stressful situation in a positive way, in Korea using humor as a coping strategy was related with poorer mental health. Social coping, such as seeking social support, was also related to poorer mental health in this population, demonstrating the different meanings and nature of coping strategies in cultural context.

Moos (1984, 2002) offers a coping and stress model that elaborates on the exchange among the environmental system, the personal system, and transitory conditions. His model investigates how the social climate and ongoing stressors interact with individuals’ personal characteristics and resources. Moo’s transactional model also theorizes that culture plays a key role, influencing each coping strategy that an individual employs, and subsequently affecting the individual’s health and well-being (Chun, Moos, & Cronkite, 2006; Olah, 1995). In cultures oriented toward individualism, personal autonomy, individual rights, and self-fulfillment are emphasized. On the other hand, collective cultures place a higher emphasis on duty and obligations to the in-group, and fulfillment of social roles (Chun et al., 2006).

Interdependent view influences an individual’s cognition, emotion, and motivation in collective cultures, such as Asian ones (Markus & Kitayama, 1991). Research has shown that strong connectedness with others is employed in coping with stress in these cultures, such as Asian American families of September 11th victims (Yeh,

Inman, Kim, & Okubo, 2006). Participants shared that their feelings of loss is not individual, but a loss for the entire family; if a family member is sick, the family is sick too. As a result, it is the family's responsibility to take care of each other during stressful times. Similarly, they seek emotional help from their friends, church members, and community. A recent study by Nguyen and Clark (2014) indicates that collectivism predicts both positive attitudes and higher levels of self-efficacy among Vietnamese American women's breast and cervical cancer screening. The authors argue that Vietnamese women may feel it is mandatory for them to take care of their health so that they can take care of their families; this perspective motivates them for cancer screening.

Although coping strategies are too complex to simply dichotomize, approach and avoidance are two basic modes of coping with stress found in the literature (Roth & Cohen, 1986). We propose a more flexible and culturally sensible approach for thinking about coping in multicultural patient populations: it may be most advantageous for pediatric cancer survivors to oscillate between approach and avoidant modes of coping. Pediatric cancer survivors should be helped to confront (i.e., actively understand and process) their thoughts and all the accompanying emotions about why they got cancer, even while sometimes forgetting and avoiding the fact that they are dealing with it. Coping should be treated as a skill that can be learned, rather than a stable characteristic like a trait. Janoff-Bulman (1992) said that traumas may shatter deeply held and unexamined assumptions about how we believe the world and ourselves to be. Testing and reevaluating assumptions can take place spontaneously through the two-track cycle of re-experiencing (confronting or approaching) and avoidance. Pediatric cancer survivors should be helped to smoothly navigate this coping "dance."

Growth

Individuals respond differently to traumatic life events. When trauma strikes, our fundamental assumptions may be reexamined or contested in the face of our own vulnerability and fragility (Janoff-Bulman & Frieze, 1983). It is hypothesized that individuals with more rigid pre-trauma views are more vulnerable to posttraumatic stress responses (Foa, Ehlers, Clark, Tolin, & Orsillo, 1999). This might suggest that children, with fewer pre-formed world views, would be less vulnerable to the after effects of trauma stress. Pediatric cancer survivors frequently ponder existential questions about life and death and its meanings, and many survivors report feeling as if they have quickly grown and matured vis-à-vis their peers (Yi & Zebrack, 2010).

Parry and Chesler (2005) explored how cancer can lead to positive psychosocial outcomes, including thriving and experiencing posttraumatic growth. Long-term survivors of childhood cancer reported a variety of positive changes, including increased psychological maturity, feeling greater compassion and empathy, having new values and priorities, recognizing new strengths, increased recognition of

vulnerability and struggle, and making changes in life outlook and coping skills. These themes are consistent with the general themes of posttraumatic growth, such as feeling a greater appreciation of life, feeling personal strength, expecting new possibilities, feeling related to others, and experiencing spiritual change (Tedeschi & Calhoun, 1995).

Positive life changes after a cancer diagnosis are commonly reported at the rate of 53–95 % in adult cancer survivors (Stanton, Bower, & Low, 2006), and growth experiences after cancer seem to be common across diverse cultures (Ho, Chan, & Ho, 2004; Kamibeppu et al., 2010; Schroevers & Teo, 2008; Thombre, Sherman, & Simonton, 2010). It is difficult to confirm what makes some people grow more than others after cancer as there is a lack of congruence regarding posttraumatic growth associations. Despite inconsistency in direction of relationship, as summarized in a study by Yi, Zebrack, Kim, and Cousino (2015), some studies have shown that PTG is correlated with minority status (e.g., Bellizzi et al., 2009), gender (e.g., Tallman, Shaw, Schultz, & Altmaier, 2010; Tang et al., 2014; Zwahlen, Hagenbuch, Carley, Jenewein, & Buchi, 2010), age (e.g., Bellizzi & Blank, 2004; Yonemoto et al., 2009), socioeconomic status (e.g., Danhauer et al., 2013; Wang, Liu, Wang, Chen, & Li, 2014), time lapsed since diagnosis/treatment (e.g., Danhauer et al., 2013), and optimism and social support (e.g., Danhauer et al., 2013; Michel, Taylor, Absolom, & Eiser, 2010; Nenova, DuHamel, Zemon, Rini, & Redd, 2013).

Posttraumatic growth is influenced by cultural factors (Calhoun, Cann, & Tedeschi, 2010); thus deeper understanding and empirical examination of pediatric cancer survivorship in the context of culture is merited. Complicating the matter, both positive and negative impacts of cancer seem to coexist. In a Photovoice project (Yi & Zebrack, 2010), which is a participatory visual research methodology, one childhood cancer survivor's self-portrait showing half of her face bright with exposure to the sun and the other half shaded is a poignant representation of the complex and Janus-like impact of cancer as a trauma. Such complexity might be inevitable, because growth can occur only with trauma major enough to transform the person (Tedeschi & Calhoun, 1995).

Posttraumatic growth is frequently associated with identity work or change in self, described as “I AM” by Grotberg (1995), as “personal competence” by Hinds and Martin (1998), and as “personal strength” by Tedeschi and Calhoun (1995). As a child experiences cancer, she adopts a social identity, or knowledge that she belongs to a social category or group (Hogg & Abrams, 1988). In this case, she self-identifies as a cancer survivor. An identity of “cancer survivor” might have different cultural connotations and meanings, but has not yet received adequate research attention. In a follow-up study of the KCCSS (Yi, Kim, Choi, & Kim, n.d.), we asked Korean pediatric cancer survivors to respond to an appropriate and preferred appellation for those who completed cancer treatment. The majority preferred “those who are cancer-cured” to “cancer survivors.” Although these are preliminary findings requiring further qualitative inquiry, we theorize that “cancer-cured” is more appealing to Korean survivors as cancer is so heavily stigmatized in their culture. “Cured” connotes separation and detachment from cancer. This obviously contrasts with other cultures, such as the USA, where those who experienced cancer are

encouraged to proactively support and advocate for each other as a community of survivors.

Posttraumatic growth is thought to be promoted by sharing, telling stories, and making sense of experiences (Tedeschi & Calhoun, 1996). Cultural factors seem to influence whom you share the cancer experience with and what consequences such cancer disclosure might bring. Gray et al. (2014) summarized in their literature review that families from collectivist cultures are more comfortable sharing information with other parents of children with cancer over friends, relatives, and neighbors. Due to stigma surrounding cancer, about half of Koreans in a national survey reported that they would not disclose it (Cho et al., 2013), likely resulting in less social support. In the KCCSS (Kim et al., 2014), childhood cancer survivors had experienced bullying, prejudicial insults, avoidance, social rejection and isolation, and discrimination during and after cancer treatment. Such stigma experiences lead them to feel self-pity, self-conscious about being different, and anxious and selective in disclosing their cancer history and building social relationships. In the KCCSS (Kim & Yi, 2014), public stigma perceived by childhood cancer survivors impacted their psychological distress through self-disclosure, internalized shame, and perceived availability of social support, demonstrating the role of cognitive and social resources in promoting psychological health even in stigmatized settings. Whether missing social interaction opportunities, due to public stigma, interferes with potential growth is a question requiring empirical cross-cultural study.

Though child cancer survivors often report becoming more resilient and ready to confront future life challenges (Rosenberg et al., 2013; Rosenberg, Yi-Frazier, Wharton, Gordon, & Jones, 2014), there is some evidence that both positive and negative effects of trauma erode over time. Posttraumatic stress symptoms seem to decline considerably for the majority of survivors within 3 months post-diagnosis or following treatment completion (Manuel, Roth, Keefe, & Brantley, 1987; Mundy et al., 2000). Similarly, posttraumatic growth may be stronger in the immediate year or two following diagnosis and treatment than after several years of survivorship (Stanton et al., 2006). In the KCCSS (Yi & Kim, 2014) shorter time since diagnosis was associated with greater levels of posttraumatic growth. Cancer is a chronic illness with physical and psychosocial late effects requiring life-long surveillance and attention (Yi et al., 2014). If resilience dwindles over time, it might be prudent to develop culturally sensitive interventions that sustain these positive effects.

Conclusion

Having examined the cultural factors that affect resilience in pediatric cancer survivorship in the previous sections, we now turn our attention to five suggested directions for future research and practice. First, further research is required to explore the way children and families communicate about and process the cancer

experience. A supportive environment for existential question-asking is an important feature of productive communication and role modeling for resilience within the family. Second, the child's social relations and resources in the cultural context should be researched, given that stigma and misunderstanding about cancer and survivorship exists in certain cultures. Perceptions and attitudes of the child's parents and friends are critical and greatly influence the child's adjustment and resilience. Mentor and mentee relationships among survivors should be encouraged, especially in those cultures where cancer history and survivorship identities are not disclosed for fear of rejection. Third, unique or aggravated challenges that specific social factors, such as gender and ethnic minority, pose in different cultures should be sensitively ethnographically studied. Fourth, coping strategies in the context of culture should be examined. The two-track approach of actively confronting and purposely avoiding the challenges of cancer may be a starting place to build an intervention. Finally, the complex dual phenomena of coexisting stress and growth in pediatric cancer survivorship should be studied. Combined, these areas for future study should reveal effective practice guidelines for promoting resilience in pediatric cancer survivors and their families. Although researchers have voiced the need for developing psychosocial interventions for children with cancer, such research is limited (Kazak, 2005). Moreover, evidence-based studies on culturally sensitive interventions are non-existent, perhaps because there is limited participation of racial and ethnic minorities in psychosocial interventions compared to their white peers (Guidry, Torrence, & Herbelin, 2005).

Because different cultural attributes and values affect survivors' behavior and participation (Guidry et al., 2005), assessment of the person's background is the key area in which cultural attributes need to be considered in developing interventions. Research has also suggested that cultural beliefs directly affect cancer control and survivorship (Aziz & Rowland, 2002; Guidry et al., 2005); thus, a "one size fits all" intervention style is unrealistic (Guidry et al., 2005). Language education and cultural competency training are also imperative for health care providers serving ethnic minority groups (Aziz & Rowland, 2002; Guidry et al., 2005). For more on fostering resilience by attending local coping practices, see Munford this volume. For example, in collectivist-oriented cultures, the relationship with the immediate family and extended family may provide Latino patients a strong support network (Nápoles-Springer, Ortíz, O'Brien, & Díaz-Méndez, 2009). A study conducted on a peer support intervention for Spanish-speaking Latinas with breast cancer indicates that involving family members could help alleviate the stress on the patient (Nápoles-Springer et al., 2009). In a shame and stigma-prevalent culture, narrative therapy intervention might be potentially effective due to its emphasis on objectifying the problem and separating the person from the problem (White, 2007).

Children who go through cancer diagnosis and treatment demonstrate resilience in different ways. Pediatric cancer patients are not just victims, but a flourishing population gaining strength from adversity. Developing culturally informed methods to strengthen resilience will positively influence cancer survivors, their family members, and their community across diverse cultural contexts.

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