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Encountering Darkness: Grieving in Korean Adolescents with Cancer

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Encountering Darkness: Grieving in Korean Adolescents with Cancer

by

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God has two dwellings; one in heaven and the other in a meek and thankful heart.

– Izaak Walton-

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Encountering Darkness: Grieving in Korean Adolescents with Cancer

Juhye Jin

Few investigators have focused on grief and bereavement experiences of adolescents themselves, especially from the perspectives of childhood cancer survivors. The purpose of this study using qualitative methods, specifically grounded theory, was to explore grief and bereavement in Korean adolescents who survived cancer following the deaths of friends to the same illness. Specific aims were (a) to explore how the adolescents coped with the death of cancer peers in particular how they interacted with their family and friends, and (b) to identify how culture impacts on their grieving. Data were obtained from Korean adolescents with cancer between the ages of 13 and 23 (N=15) through semi-structured interviews (face-to-face interviews, telephone interviews, and Internet chatting), observations of the social dynamics of participants within self-help groups, and retrieving personal Web journals. Data collection and analysis were conducted simultaneously, and constant comparative methods were used for analysis. Field notes from interviews or observations and memo-writing were integrated into the analytic process. Findings were grouped into three parts. First, participants coped continually with reminders of their grief while interacting with themselves, friends, and their family. To avoid the distress of grieving, participants kept silent, sought solitude, and took care of themselves and others. Second, participants put their grief aside and worked to ease their mother's burden. The conceptual components of filial piety were linked to the ways in which participants made efforts to not show their grief in front of their mothers. They strived to meet parental expectation of carrying on the family lineage, hid their own burden to lessen their mother's worry, reassured their mothers that they will reciprocate the care they received, and attempted to tactfully sense their mothers' feelings and thoughts. Third, cultural considerations such as gate-keeping and multiple strategies to collect data from Korean adolescents were refined based on the understanding of the collectivist culture. The resulting conceptualization of grieving, a theoretical application of filial piety, and methodological reflections will be the basis for future comparative research in grief and bereavement of other cultures, both in Asia and Western countries.

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CHAPTER 1.

INTRODUCTION

Adolescents with cancer are positioned between the world of healthy peers at school and the world of cancer peers, within the context of their family (Keene, Hobbie, & Ruccione, 2000). Even upon completion of their cancer treatment, they might be concerned about the welfare of both their cancer peers and themselves, such as whether their cancer has recurred or if they have entered a dying trajectory (Kelly, Pearce, & Mulhall, 2002). The surviving trajectory of adolescent cancer survivors is just extension of their illness trajectory, and the adolescent survivors are also influenced by how they view themselves and by their interactions with others such as families and friends. Their losses are embedded in their life, and involve an interplay between the tasks and conflicts integral to the phases of adolescence (Balk & Corr, 2001). However, little is known about grief and loss experiences of adolescents who had cancer.

Researcher's Background

Since my first experience of caring for children with cancer in the mid 1990s, the arena of pediatric oncology nursing has motivated the focus of my academic journey. As a novice nurse, I was devastated to see the suffering of children with cancer, and I eagerly sought hands-on interventions for these children. As time went by, I found myself wanting to be better armed with more knowledge in psychosocial care and in how to provide support to the children rather than becoming simply a clinical nurse with excellent clinical knowledge and procedural skills. I found that reading even up-to-date textbooks or articles in the library was not enough to obtain the necessary knowledge for providing optimal psychosocial nursing. The knowledge I sought seemed to be beyond what was already known, and I was motivated to begin a journey of exploring the deeper and inner lives and worlds of the children and their families. For example, I wanted to know how children with cancer and their families, after lengthy hospitalizations, experienced the time when the children returned to school and related once again with healthy peers [investigated in my master's thesis]. I was also curious about feelings of uncertainty that children with cancer might develop after completing their cancer treatments, and I wondered about the children's potential for morbid thinking resulting from repetitive exposures to the deaths of cancer peers along the trajectory from illness to survival.

Concerns about how children with cancer cope with the deaths of friends who also had cancer were frequently aroused when I myself grieved over the deaths of the children for whom I cared. I particularly paid attention to adolescents with cancer based on their developmental challenges of constructing a sense of self-identity and abstract thinking capacity (Christie & Viner, 2005). I assumed that the adolescents were apt to engage in thinking about existential issues pertaining to their own life and death as well as questioning themselves. Consequently, I chose to focus my doctoral research on how adolescent cancer survivors coped with the death of cancer peers.

Pilot Study

In the summer of 2004, I conducted a pilot study using interpretive methods and focusing on the lived experiences of Korean adolescents with cancer who had lost peers to cancer. Data were collected through in-depth interviews with three male adolescents in community settings. One interview with a female adolescent was done over the phone; during this interview I heard a variety of emotions and thoughts that differed from the responses of the male adolescents although the interview was conducted by phone. I thought the invisibility between interviewer and interviewee might be advantageous in the interviewee being better able to describe her experience with the sensitive topic pertaining to dying, death and grief.

In addition to the formal one-hour interviews, I conducted informal interviews with each participant during follow-up due to my concern that the participants might experience some emotional distress after sharing their sad stories. During these conversations, the participants discussed their values and thoughts, some of which were not revealed in the formal interviews. Though not tape-recorded, the data from these conversations were integrated into analytic memos and field notes which were helpful in data analysis. All participants were more comfortable sharing their inner stories during the informal interviews, supporting my expectation that participants may need some time to open up to the researcher. The importance of multiple interviews and an informal atmosphere with adolescents were incorporated into my dissertation project. As well, participants informally told me about their own personal Internet homepages, and that they tend to keep diaries or journals on the Web that are open to the public. Indeed, these sites also served as a source of data for my dissertation study. Using the Web to communicate with others and to express feelings in the form of journaling is common practice in Korea where 59.5% of the teen population has personal homepages (National Internet Development Agency of Korea [NIDA], 2007). Journals on homepages are openly shared with the public, so that reading them is not considered invasion of privacy.

Findings showed that the adolescent survivors' grief was embedded in their current lives as cancer survivors. Their physical bodies played a role in connecting memories of deceased friends to current fears of possible relapse and their own future deaths. Their grief was intermittent, triggered by memories of death events in the hospital as well as by current happenings in their lives, such as hearing bad news about a cancer peer. Their response to grief focused on surviving and creating relationships with family members and friends who remained alive. The emphasis on social relationships in their grief came to be the primary motivation for switching to grounded theory methods for the conduct of my dissertation project. As well, the need for multiple modes of data collection fit well with grounded theory methods. How social processes are involved in grieving among Korean adolescents who survive cancer following the deaths of their cancer peers?

Dissertation Study

My dissertation study used qualitative methods, particularly Grounded Theory, to generate knowledge regarding grieving in Korean adolescents with cancer following the deaths of friends to the same disease. Specific aims were to examine how adolescents coped with friends' death to cancer, noting in particular how adolescents interacted with their family and friends both with and without cancer, and to identify cultural impacts upon their grieving. In addition to conceptions about loss, grief, and bereavement in Korean adolescents with cancer, a central concept of "relationship" passed through the aims mentioned above. Their relationships were influenced by interwoven societal relationships and values, and no doubt will continue to evolve as the adolescents move into new social worlds. Because relationships are derived from how people act toward each other, my focus on relationships fits with Symbolic Interactionism (SI) that underpinned the grounded theory methods I used (Blumer, 1969/1998). Three types of relationships were examined from the perspective of SI.

The first type involves interpersonal relationships, in which grief and bereavement theorists have focused on believing that the way a person grieves depends on his or her relationship with the person who has died. Interpersonal connections can be extended beyond the close relationships between the bereaved and the deceased. For example, bereaved adolescents were not only concerned about their memories of their deceased friends, but they also invested emotional energy in caring about their family members or friends who were alive (Chapter 2). Intrapersonal relationships can refer to how grieving individuals relate with themselves based on the fact that an individual has a self, enabling him or her to interact or relate with him/herself (Blumer, 1969/1998). For example, the grieving adolescents adhered to their inner values of filial piety when thinking about their mothers (Chapter 3). Lastly, extra-interpersonal relationships involve the interconnections between the grievers and their society. How cultural and developmental aspects influenced adolescent interactions with the researcher inspired "lessons learned" about cultural sensitivity in conducting this research and for other researchers (Chapter 4). All three levels of relationship are illuminated in the three papers that report the findings of this study.

Overview of the Dissertation

The dissertation is divided into five chapters. This foregoing introduction (Chapter 1) briefly describes the background for the study, the pilot study, and the purpose and aims of the study. Chapter 2 reports the major findings pertaining to how Korean adolescents, after the loss of their peers with cancer, coped with reminders of the "darkness" that characterized their generalized grief. Chapter 3 presents a pivotal theoretical aspect of the dissertation findings – the concept of filial piety. Specifically, the paper describes how Korean adolescents worked to ease the burden that they perceived their mothers carried as a result of their child' illness. Chapter 4 offers a detailed description of methodological considerations when collecting data from Korean adolescents with cancer. In particular, issues and strategies relevant to Confucianism and collectivism are examined. Chapters 2, 3, and 4 will be submitted for publication to the Journal of Pediatric Oncology Nursing, the International Journal of Nursing Studies, and the Journal of Advanced Nursing, respectively. Lastly, Chapter 5 addresses the three papers as a whole (Chapter 2 to 4) and discusses implications for practice and future research.

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CHAPTER 2.

ENCOUNTERING DARKNESS: GRIEVING IN KOREAN ADOLESCENTS WITH CANCER

Encountering Darkness: Grieving in Korean Adolescents with Cancer

Abstract

Few research studies have examined grief in adolescent cancer survivors who face constant loss. Their grief is caused not only by the spectre of death, theirs and others, but also by their experiences of recovery and living in the world as cancer survivors. In this article, the authors describe how Korean adolescents with cancer encounter darkness, which is rooted in fear, worries, and concerns about cancer recurrence, death, and the impact on their relationships with others. The adolescents' grief was triggered by introspection and interactions with family and friends. Three strategies emerged from this qualitative study that explain how these adolescents avoid the darkness: keeping silent, seeking solitude, and taking care of self and others. The adolescents' avoiding and encountering grief occurred simultaneously, propelling them up and down the spiral of darkness.

Keywords: Adolescents, Cancer, Grief, Korean

Along the trajectory from illness to survival, adolescents with cancer experience numerous losses. And, those who survive the disease anticipate further losses in the future. However, health care professionals poorly understand this population’s loss experiences and grieving. For example, fearful that their medical condition might worsen and cause conflicts with family and friends, these adolescents experience additional stress and grief. And, they deeply grieve for cancer mates who have died. As grievers grappling with continuing losses, adolescent cancer survivors have been understudied. This article focuses on Korean adolescents who have survived cancer. They are a vulnerable group for unique cultural and developmental reasons that will be reported in this article.

First, Koreans who espouse Confucianism tend to avoid burdening others and are sensitive to words and behaviors that might offend those whom they know (On-line Confucian Museum, 2002). Thus, Korean adolescents might mask their grief to spare their parents this added burden. Close-knit family relations also inhibit how adolescents grieve. In Korea, young adult cancer survivors, unlike other young adults, often live with their parents rather than leave home to establish independent lives. More important, if an adolescent survivor is the first-born son, he has a “cultural duty” to provide care for his parents when they get old (Im, 2005; Park & Cho, 1995).

Second, experiencing cancer affects how adolescents view themselves and how they interact with family and friends. Confronting the challenges of physical, psychological, and social changes, these adolescents grapple with such profound questions as “Who am I? How should I behave? and How do I fit into society now? (Harter, 1999; Neville, 2000). Clearly, these adolescents deal with far more internal conflict and stress than teenagers without cancer. This article reports findings from a study of how Korean adolescents who survive cancer cope with grief and how their grieving is interwoven with their experiences of cancer.

Review of the Literature

Few researchers have investigated grief in adolescent cancer survivors and its effect on their lives. The following review explores Western knowledge of grief and cancer in adolescence.

Adolescent Grief

Most of the studies published in English have examined the bereavement process that adolescents experience following the death of a sibling or a parent rather than the death of a friend. However, a few studies of peer loss, conducted in the early 1990s, are noteworthy. Although these studies were limited to healthy teenagers, especially those in late adolescence, the results show that adolescent grief is characterized by intense thoughts of personal identity and difficulty in talking about their grief (McNeil, Silliman, & Swihart, 1991; O'Brien, Goodenow, & Espin, 1991; Schachter, 1991/1992).

The authors above have discussed adolescent defense mechanisms such as avoidance, vulnerability in dealing with emotions, and features of the family environment that allow adolescents to get closer to their parents and to learn how to grieve by observing them. O’Brien and colleagues (1991) further addressed the social relationships of bereaved adolescents and how such ties can deepen after loss. Post-loss relationships with parents and peers depend on the quality of those relationships before the loss. However, Rask, Kaunonen, and Paunonen-Ilmonen (2002) reported that support from family or friends was not always helpful. Instead, self-help proved to often help adolescents in grief.

Several researchers have made significant contributions to our knowledge of grief after the loss of a sibling, such as understanding the concept of shared life space and grief responses (Davies, 1988), the effects of time on sibling bereavement (Davies, 1991; Hogan, 1986), the effects on the development of the surviving sibling (Balk, 1983b; Hogan & DeSantis, 1992), the role of self-concept perceptions (Balk, 1983a), and factors that help and hinder sibling bereavement (Hogan & DeSantis, 1994). These authors have highlighted the bereaved sibling's developmental context and family dynamics and found that a sibling's understanding of death, previous experience with loss, coping styles, and the degree of closeness to the deceased affect his or her adjustment after loss.

Cancer in Adolescence

Adolescence is a dynamic and complex period in human development that becomes more complicated when cancer occurs (Lewis, 1996; Rainey, 1982; Stuber & Kazak, 1999). Experiencing cancer affects physical, psychological, and social changes that occur throughout the phases of adolescence (Klopfenstein & Young-Saleme, 2002). Altered physical appearance (e.g., hair loss or change in hair texture, "moon face", acne, obesity or low weight, decreased energy, skin pigmentation, or surgical scars) is a major concern for adolescent cancer survivors. Obsessing over an altered body image makes adolescents with cancer feel exposed, unworthy, and stressed when relating with others (Larouche & Chin-Peuckert, 2006; Pendley, Dalhquist, & Dreyer, 1997). Negative self-identity caused by changes in body image persists for a long time, even several years after treatment (Pendley et al., 1997). And, adolescents with cancer have fewer friends than healthy adolescents, which can accelerate an adolescent's social withdrawal (List, Ritter-Sterr, & Lansky, 1991; Neville, 2000).

The development of *abstract introspection* in middle adolescence can stimulate adolescent cancer survivors to become deeply introspective. Their concerns and conflicts about managing cancer and its aftermath collide with the rapid changes in the physical, psychological, and social aspects of their lives (Heiney, Wells, Coleman, Swygert, & Ruffin, 1990). At this developmental stage, adolescents become more spiritual when contemplating their own death (Balk, 1991, 1999). Their reflective thinking may also include an increased awareness of death because they have been surrounded by others with life-threatening conditions and experienced the death of peers from cancer.

Identifying a *social self* can be more complex in adolescents with cancer because a social self is shaped over time by interactions with people in various places (Harter, 1990; James, 1890/1999). Adolescent cancer survivors construct and reconstruct relationships with peers, family, and others during the transition from adolescence to adulthood. They also can adopt a new philosophical outlook during the illness experience and try to think positively about themselves interacting with others (Weekes & Kagan, 1994).

Owing to their egocentricity (Elkind, 1967), adolescents may think that parents and friends expect them, as cancer survivors, to be functioning well and to be strong enough to overcome any difficulty, even a friend's death. And, adolescent survivors might be self-absorbed, more concerned about their own survival than about others.

In sum, relevant studies of grief and bereavement in adolescence suggest several factors that might affect how young people with cancer grieve over the death of a peer from cancer: the developmental features of individual adolescents, adolescent coping mechanisms, previous life and loss experiences, the nature of the loss, and an adolescent’s interpersonal relationships.

Methodology

Study Design

This study used grounded theory (Charmaz, 2000; Strauss & Corbin, 1998), a qualitative research methodology, to understand grief in Korean adolescents who have survived cancer.

Setting and Participants

Fifteen Korean adolescents aged 13 to 23 who survived cancer participated in the study, 13 males and 2 females. Registered at a large cancer treatment center in Seoul, Republic of Korea, all were less than 5 years into complete remission at the time of the study. Most of the adolescents regularly visited the outpatient clinic for follow-up care every 3 or 6 months and participated in a monthly self-help group at the hospital. Those who suffered from severe cognitive dysfunction due to cancer treatment and those diagnosed with a previous or current psychiatric disorder, such as depression, were excluded.

Data Collection

Participant recruitment. The process of recruiting study participants included the posting of flyers in a university-affiliated hospital in Korea, physician referral, and word-of-mouth among the participants. Interested adolescents, visiting the hospital for their routine follow-up, contacted an oncologist in charge of the pediatric population with cancer or the study investigator (the first author) by telephone or email. Informed consent, for adolescents aged 17 or older, and patient assent from those aged 13 to 16 was obtained at the first interview. All of the consents and assents required parental signature. Approval for this study was obtained from the institutional review boards of the local center in Korea and the University of California, San Francisco.

Participant interviews. Interviews with semi-structured questions were conducted by the first author to collect data. Participants selected the type of interview: a face-to-face interview, a telephone interview, or an Internet chat. Each adolescent participated in at least 2 of the following types of formal interviews, for a total of 9 face-to-face interviews, 4 telephone interviews, and 17 Internet chats. They also had 1 to 3 additional informal interviews, primarily through Internet chatting. Questions addressed topics such as the participants' view of themselves as cancer survivors, daily interactions with their family and friends, and situations that make them sad. Probes were used to encourage participants to clarify and expand their responses. In-person interviews, which lasted 60 to 90 minutes, were conducted in Korean in a location designated by the adolescent interviewee (the participant's house, a community playground, or a fast-food restaurant). Interviews were tape-recorded and transcribed verbatim into Korean and then translated into English. Field notes and analytic memos were written in Korean and translated into English. The English translation was done by the first author and checked by native-born, English-speaking colleagues. Back translation was needed for some texts to validate that accuracy of the translation; the English documents were back translated into Korean for further validation of accuracy.

Observations. In addition to the interviews, observations were conducted at the monthly self-help group meetings, and were crucial in understanding the shared meaning of participants' behaviors. To get an overview of participant members in social interaction, the first author made descriptive observations. She had two opportunities, at these meetings, to observe how the adolescents communicated with one another on hearing that one of their friends had passed away.

Accessing Web-based materials. Young Koreans commonly have their own homepages on the World Wide Web (the Web), called *Mini-hompi* or *Cyworld*. Written messages on the adolescents' homepages allowed the researcher to view the participants' concerns, what they were saying among themselves, and how they expressed themselves. The investigator and participants mutually agreed to use selective Web functions, such as diaries and visitors' logs. Participants allowed the investigator to retrieve their previous and ongoing public diaries, which described how the adolescents were doing. Although participants were asked to write journal entries whenever they were reminded of their deceased friends, no one did. However, the visitors' logs provided the investigator and participants with a vehicle for secure mutual communication about their grieving processes and other topics.

Anticipating that participants' might find the formal one-hour interviews emotionally distressing, informal interviews were also conducted with each participant. During these informal conversations, participants shared their values and thoughts, some of which were not revealed in the formal interviews. Most of the data from the informal interviews were not tape-recorded but were integrated into analytic memos and field notes, which aided data analysis. All participants were more comfortable sharing their personal stories during the informal interviews, supporting the authors' supposition that they might need further time and a variety of communication formats to share their innermost thoughts and feelings. The study's design anticipated the importance of multiple interviews and contacts establishing an informal atmosphere within which the adolescents could comfortably express their thoughts and feelings.

Data Analysis

Data collection and analysis were conducted simultaneously, and constant comparative methods were used to generate and analyze data (Charmaz, 2004). Codes were developed, revised, and used to recode previously coded data. Codes were grouped into theoretical categories and relationships among the categories were identified. Field notes from interviews or observations and memos were integrated into the analytic process. Charmaz' four principles of quality criteria were used to ensure rigor (Charmaz, 2004). First, the primary author gained familiarity with the phenomenon in our study, by engaging with adolescents with cancer in activities over several years in clinical practice and as a volunteer, such as at summer camps and self-help group meetings. To establish theoretical perspectives, the authors met regularly to scrutinize and discuss data in relation to the developed categories. The first author also often went back to participants to verify interpretations (member checks). To ensure that we were being faithful with the phenomenon under study, we focused on constant comparative analyses of data within and across participants, using a variety of references from other studies about grief to assist in exploring ideas and writing memos. To fully understand the Korean adolescent oncology population, the first author had ongoing discussions with health professional colleagues in Korea.

Findings

This study's primary focus was to explore how Korean adolescents with cancer experienced the death of children or adolescents who also had cancer. In their interviews, however, the bereaved adolescents chose not to dwell directly on the loss of their cancer mates. Rather, when asked about their experience following the death of friends, participants queried, “Why do you want me to talk about such dark stories?” In response, the interviewer probed the meaning of the term “dark.” Initially, we thought that the participants were reticent to talk about death. But, with further prompting, the participants shared memories of their peers who had died and discussed their own reactions to the deaths. Importantly, there memories of their friend’s deaths triggered stories about living with cancer. The participants appeared more concerned with their losses in the broader context of their life after cancer than the narrower topic of the death of their peers. For the participants, “dark stories” referred to the darkness they encountered in their overall experience of cancer, with grief over a peer’s death only one of the losses they encountered.

Encountering Darkness

Participants encountered darkness when they were reminded of their cancer and its effects on their life, which included physical changes, interactions with friends, and concerns about family members.

Physical reminders. The principle source of darkness was physical changes. Even after complete remission, the participants continued to worry. Although they were relieved to be cancer-free, the adolescents were acutely aware of any visible physical changes caused by the cancer and its treatment, such as surgical scars, restricted mobility, or cosmetic alterations. Invisible changes, such as lack of energy or fatigue and not feeling well, were also of concern. These changes caused participants to constantly worry that cancer might recur and to feel uncertain about their future. Whenever the adolescents experienced what may have been a “normal” illness, such as a cold, their concerns were magnified. At such times, participants were reminded of the extreme darkness, death. An 18-year-old young man who survived a mandibular tumor commented:

> I remember it was a few days ago when I failed to fall asleep. I don’t know the reason, whether it was due to my bad cold or from tiredness after a big test at school. I ran into my bed right after coming home, but I woke up around 11 p.m. Mom told me to keep sleeping, so I went back to my bed for more sleep. I felt really, really tired. Around midnight, I woke up from sleep again because I felt some chills. So I pulled my bedclothes over my head. At 1 a.m., I woke up again due to a terrible headache. I couldn’t get back to sleep anymore. I was groaning and groaning. My headache - the suffering made me fear death, which I didn’t even feel when I was ill before. I was crying sorrowfully for 10 minutes or so, covering my head with the bed sheets, struggling with the bad headache. At 6 a.m., I found that I was wet from both sweat and tears.

Peer reminders. Interactions with peers, those healthy or with cancer, also reminded participants of the darkness. While undergoing cancer treatment, many participants felt different from their classmates; they had fear of being stigmatized or alienated from others even when their diagnosis was secret. Hoping that their peers would not learn of their cancer, the participants often tried to hide any evidence of their disease. They avoided mentioning their diagnosis when meeting new classmates or socializing with classmates who knew of their cancer. If friends asked questions, the adolescents would answer briefly but without details. Even after treatment, unpleasant memories of alienation were a source of darkness. Those feelings persisted and resulted in feelings of isolation even when the adolescents interacted with healthy peers who were close friends. Participants, however, had few close friends without cancer. A 16-year-old boy who survived Ewing's sarcoma commented:

> Most of my friends don't know I had cancer treatment in the past. They just know that my leg is easy to break and I need to be hospitalized often. They don't know about my cancer, because it happened back in elementary school. I don't talk about it. Only three or four old friends know about it.

An 18-year-old young man who survived a brain tumor added:

> You can't imagine how hard it was for me to make friends when I went back to school. Every time I approached a classmate, it was hard and I would think back to how difficult it was before. That's why I only have a few friends now.

Remembering peers who died from cancer also prompted participants to encounter darkness. They remembered fellow patients who underwent treatment when they did, who were members of their self-help support group, or who attended an annual summer camp for adolescents with cancer. When one of their cancer mates died, participants were shocked by the news even though they had witnessed their friend's declining health. The 16-year-old boy who survived Ewing's sarcoma commented:

> We [the campers] were waiting in line. I was right next to him. I saw him faint. Then his body started to shake. It was very scary to me. 'SJ is dying' I screamed. I couldn't keep from bursting into tears. Shortly after he was transferred to the hospital, he went to Heaven. Oh, darn! He really died. I shouldn't have said that [dying]. Since I experienced that, I haven't gone again to the summer camp for teens with cancer.

When informed of a cancer peer's death, participants were initially angry, especially if the news was late. Anger eventually turned to regret for not having the chance to say goodbye or having spent time with their friend. After such a death, participants felt sad and vulnerable because it reminded them that they could have suffered the same fate. A 15-year-old boy who survived leukemia explained:

> I remember when JY and I played together. Sometimes, when I'm reading a book or studying for an exam… doing something like that in my bedroom, JY [deceased friend] suddenly comes to my mind. I mean, in the middle of studying, his memory flashes across my mind. I think for a little while, stop studying, and keep thinking. But I try to forget and get back to work again once I feel okay. Because, when I keep thinking, it often makes me feel sad. I don't want to feel sadder.

Another leukemia survivor, an 18-year-old young man, added:

> When I first heard the news, I couldn't believe it. I felt stunned. I thought he was okay. I couldn't imagine he would die soon. I felt a bit guilty. I should have come to see him when he was having a hard time by himself. I feel really bad whenever I think about how he was lonely then. I imagine what it would be like if I died, and who would come to see me at the last moment.

Family reminders. Reminders of facing darkness were also fueled by family relations. Participants became sad when reminded of the hard times their parents endured caring for them. They were aware of what their families expected of them and how they could meet those expectations. Not wanting to burden the family any further, the adolescents hid their worries and concerns. They avoided emotionally-sensitive situations with their families and pretended not to show pain in front of their parents. A 15-year-old boy who survived leukemia said:

> My mom fainted right in front of me. She must be really tired of taking care of me in the hospital. I thought that was the saddest moment in my life. I kept crying and squeezing her hands. I have an older sister, but she can't take care of my parents [when women in Korea get married, they leave and become outsiders to their own families]. So I had to stay healthy to take care of my parents when they get old. I also need to make lots of money to clear the debts my family incurred from my illness.

An 18-year-old young woman who survived leukemia concurred:

> My mom has never told me about how hurt she felt by looking at me [in the hospital], but I could tell. She had been pretending she was okay, so I didn't want her to see my pain. I don't want her to see how sad I feel. I only want to show my smiles to my parents.

Worries about health and fear of caused by physical changes, distress in peer interactions, and concerns about family are what participants referred to as the darkness. This darkness weighed upon them and resulted in participants feeling uncomfortable, distressed, and sad.

Avoiding Darkness

Participants experienced darkness in their everyday lives as they were inevitably engaged in self-reflection and interactions with their families and their peers (See Figure 1). Their reflections and interactions triggered the darkness. As if following the downward rings of a spiral, the deeper the adolescents descended into darkness, the more they seemed vulnerable to experiencing even more darkness, such as the fear of death. To reverse their downward journey, the adolescents made ongoing efforts of keeping silent, seeking solitude, and taking care of themselves and others.

Keeping silent. Participants avoided discussing their anxiety about cancer recurrence, the fear of their own mortality, traumatizing past experiences of bullying, and worries about family members. Once they expressed such emotions, they knew that they could not avoid thinking of dark situations, which created a vicious downward spiral. Instead, they decided to stop talking or thinking about those experiences. Silence kept darkness at bay. A 19-year-old young man who survived leukemia said:

> I'm just not going to think about death. It's horrible and scary, isn't it? We don't know what comes after death, do we? That's the most terrifying thing. So, I try not to think about it to ease my mind. Sometimes I get insomnia because of my repetitive negative thoughts [morbid thinking]. I probably should talk to someone about that, but I don't want to.

All participants were initially hesitant and reluctant to air these dark feelings. Only when the first few revealed their stories did the other participants "open up" with theirs. One participant said, "I wonder what you [the interviewer] have heard from others about their experiences. They must have had a hard time telling you. What did they say?" Avoiding dark feelings was also evident in how participants dealt with bad news in a self-help group. When someone died from cancer, the news was not shared with everyone at the same time nor was it open for discussion. Group members worried about the darkness caused by dark topics. A 15-year-old male leukemia survivor explained:

> I was very upset because the others didn't tell me the news that he died. How

> could they do that to me? They said they didn't want me to feel stunned. I know how much they worry about me, but I should have known the truth. I really had a hard time dealing with the news for quite a while. It was terrible.

Seeking solitude. Participants sought solitude to deal with dark issues. Remembering a friend who died or thinking about one's own mortality typically occurred in the privacy of the participants' bedrooms. Although they avoided mentioning their darkness, the participants hinted that they succumbed to it. A male 17-year-old lymphoma survivor remarked:

> Sometimes I grieve in my room by myself. Whenever I'm feeling down, I lock my bedroom door and sit in the corner. I think and think about what's going on. Then I think about what I'm going to do. To avoid being so sad, I usually play computer games or watch TV if I burst into tears.

A 15-year-old boy who survived leukemia added:

> Remembering ought to only happen in my mind, I think. It's my own thinking. I don't want to be bothered. I mean, it should be something that only I know about. I shouldn't talk to anyone about it, just think by myself.

A 19-year-old young woman who also survived leukemia commented:

> I thought about death by myself a lot. My thoughts would wander because of my disability in those days. I couldn't sleep well back then. I just wanted to die [short pause] in this bad world, I would rather choose to die, I thought. But, that didn't mean 'suicide.' It seemed like dying would be scarier than my suffering then. There is nothing left after death. So, I just turned my thoughts toward the future and making a life again.

She thought at first that death might be easier than her suffering, but then she realized that death was very frightening and chose to concentrate on the future. Spending time alone seemed to provide participants with an opportunity to consider strategies for dealing with darkness, and positively impacted their emotional state. A 15-year-old boy who survived leukemia said:

> I should be alone to remember him [a deceased friend]. I think about him when I'm doing my homework or watching TV. I think about the times we had together. Sometimes the memories make me feel happy, but not always. If I start feeling sad, then I stop thinking and do something because I don't want to be in such a mood… I have a big stuffed bear in my room. Whenever I feel distressed, I hit it until I feel better. Once I calm down, I can start to think about myself, my friends, and family. I should thank my bear, which is almost worn out.

A 19-year-old young woman who survived leukemia opined:

> I read the Bible to escape my fears, read some books about Christians, listened to some hymns, and started keeping a secret diary. For example, I wrote, 'I feel bad now, because there was something wrong with one of the children who were close to me.' I just wrote down my moody feelings.

A 17-year-old boy who also survived leukemia commented:

> I took a walk, thinking about what went wrong and what I had to do. I just wanted to walk and walk alone because that helped me to stop thinking.

Taking care of self and others. While dealing with darkness in silence and solitude, participants also showed a strong tendency to take care of themselves, their friends, and family, during their grief around a peer's death. In avoiding dark thought, participants first paid attention to taking care of themselves, in particular their own bodies, and worked hard at everything they did. To catch up with healthy peers, for example, they made efforts to become physically fit and to live healthy lives. A 15-year-old boy who survived leukemia commented:

> After his [my friend's] death, I resolved to take better care of my body. I have to do *Mom-jo-ri* to prevent relapse ['*Mom-jo-ri*' usually refers to what women do for postpartum care in Korea, a regimen that involves nutrition, sleep, and rest.]… Playing only at home isn't good for my body. So I often take short walks after meals or do light exercise outside the house. I just don't go around outside very much. I don't eat strange things. As you know, there are many things on the streets, I mean, things like junk food that people in the streets usually sell. I don't have that kind of stuff. I also don't eat raw fish.

A 19-year-old young man who survived a solid tumor said:

> Well… after hearing that [about the death of my friend] … I think it's difficult to express how the situation was for me… [short pause]. It was something different… I mean, it was more of a stunned thing than a sad thing… as if time stopped short. However, I told myself that I had to get out of the shock. So, I thought over and over about where I was going and what I had to do right then. Finally I thought I should buckle down in life. I thought I had to earnestly start my fight for survival and I wanted to play my part… I promised myself that I must not pass my time idly. I thought that would be the best way to remember my [deceased] friend. Even now, my convictions are unchanged.

Participants were also concerned about taking care of their friends who had cancer. They were solicitous of their friends' emotional and physical health because of their shared experience. Participants understood their friends' situations and were concerned how they were doing. These concerns again triggered thoughts about themselves. An 18-year-old girl who survived leukemia concurred:

> I want to check on other friends in the group… how others are doing… whether they are sick or alone at home… I felt very glad when I found out that other members were worried about me when I was absent from the last meeting.

Finally, participants found it intolerable to see their family suffering from darkness. They did not want their family members to worry about them anymore; they wanted their own survival and improving health to continue forever for the sake of their families. Participants knew that being strong, happy, and well would protect their families from burden. They felt it necessary to hide their own darkness that resulted from both physical and emotional difficulties. A 17-year-old boy explained:

> …my current school friends and my family are more important. I might be sad whenever I hear about someone's death, but I'm not going to be concerned about it. My family has had a difficult time for a long time because of me. I do not want to hurt them anymore.

A 19-year-old young woman agreed:

> I really don't want my mom to see me cry. I need to be stronger in front of her. If she saw me cry, she would be sad because of me. She has dealt with so many difficulties already… One day I didn't feel good…I felt nauseated and vomited a lot. I didn't want my mom to see me because she would definitely feel bad again. So I went to an emergency room near my home by myself and got IV fluids. My

mom still doesn’t know about this. It’s a secret between you and me.

In sum, the darkness that adolescent participants experienced was triggered by interactions with themselves, with friends, and with their family. To avoid the darkness, the adolescents followed three paths: keeping silent, seeking solitude, and taking care of themselves and others. Thus, avoiding and encountering darkness occurred simultaneously, propelling the adolescents up and down the spiral of darkness.

Discussion

This study examined how Korean adolescents who survived cancer grieved for a peer who died of the disease. The findings, however, indicate that the death of such a friend was only one of several cancer-related experiences that resulted in a persistent ever-deepening darkness. This darkness was rooted in the cancer-related losses that participants experienced throughout the course of their illness and recovery. The fears, worries, and concerns accumulated throughout their illness seemed to envelope them in grief. Like *anticipatory grief*, their fears of cancer recurrence or of dying as their friends did contributed to their dark thoughts (Breyer, Sanfeliz, Cieurzo, & Meyer, 2006; Martin & Doka, 2000). Participants’ feelings can also be characterized as *disenfranchised grief* (Doka, 1989) because their darkness, or grief, was hardly recognized by family, friends, and even health care professionals. The adolescent grievers were instrumental in trying to hide their grief from others. They appeared to bring about their own disenfranchisement.

The darkness that the participants experienced, expressed as fears, worries, and a descent into further darkness, could be interpreted as depressed feelings. Indeed, the participants described feeling depressed at times, but we hesitate to conclude that it was a clinical condition. First, none of the participants was diagnosed with depression even though they were under medical supervision. Second, none had suicidal ideations, and they were critical of people who did. Third, they were consciously proactive in overcoming their darkness, rather than succumbing to it. Thus, the darkness the participants encountered was sadness associated with grief for their many actual and feared losses. Moreover, they were periodically sad, worried, and fearful of what lay ahead (e.g., cancer recurrence or death) and melancholic about their potential death's affect on their family.

Grief resulting from fears, worries, and concerns has been seldom mentioned as a response to loss among adolescents with cancer. Other researchers of adolescents or young adults with cancer have classified such responses as psychosocial well-being (Woodgate, 2005) or "feeling states" (Woodgate, 2008), "a lot of mixed feelings" (Papadopoulos, Guo, Lees, & Ridge, 2007), ongoing worries and concerns (Parry, 2003), or simply suffering (Carlsson, Kihlgren, & Sorlie, 2008; Fochtman, 2006). Our findings suggest that all those components can be encapsulated under the general framework of grieving and such a framework might provide insight into how adolescents cope with cancer.

In their study of children coping with cancer, Phipps and colleagues (1995) indicated that avoidance is a common response. It was also a central finding in our study. Although avoidance may be a common behavior among those with cancer, it was also embedded in the participants' culture. In their study of Chinese young adults, Papadopoulos et al. (2007) reported three aspects of avoidance comparable to our findings: avoiding conversation about cancer because of its societal stigma, avoiding hurting family and friends, and avoiding "gloomy" subjects (p. 428), as our participants avoided dark stories. A recent qualitative study of breast cancer survivors also addressed how the cancer survivors had a hard time restraining their true feelings when relating with others (Yoo, Aviv, Levine, Ewing, & Au, 2009). The authors found that elements of what they called “emotion work” included managing their family’s worry and protecting and soothing others. Of particular note is the desire to avoid hurting family. Because our participants grieved in anticipation of their family’s distress, they sought not to burden them further. Although the notion of “burden” as it pertains to terminally ill adults and their grief has been discussed in the literature (Johnson, Sulmasy, & Nolan, 2007; Wilson, Curran, & McPherson, 2005), these adolescent cancer survivors in Korea, and perhaps all Asian countries, revealed that avoiding burdening their family is their highest priority. The effort involved, however, only reinforced their grief and sense of isolation.

Moreover, it was not surprising that our participants sought solitude to spare their family members from further burden. Aloneness might be associated with caring about another person’s vulnerability, or burden. A phenomenologic study on breast cancer survivors’ loneliness similarly mentioned that the women felt they needed to maintain an image that did not reflect their fears and burdens (Rosedale, 2009). By attending support groups, these women formed connections and also became concerned about each other. The question arises how burden-bearing in solitude impacts a cancer survivor’s coping or grieving by different age groups or ethnic populations. This suggests the need for further comparative studies across various cultures and illnesses.

Our participants’ concern for their family seems similar to the increased closeness and desire of adolescents with cancer in Western countries to “be there” for their family in appreciation for their care and support (Woodgate, 2006). But, our participants’ concern went beyond appreciation; it seemed more like a duty, a responsibility to stay healthy in recognition of their parents' care and concern. Similarly, O'Brien and colleagues (1991) discussed the interpersonal context of adolescent grief, advocating that bereaved adolescents' current relationships with parents and peers be considered. They reported that half of the grieving American adolescents they studied reported feeling disappointed by their parents' responses. Those who felt less parental support also had difficulty finding someone to talk with about death. In our study, participants indicated that their family offered relatively little support as they dealt with darkness or grief, even though they did not expect such support. Our Korean participants took that in stride. Rather than seeking support from family members or even initiating communication with them, our participants tried to protect loved ones by hiding their struggles. Thus, cultural context is a vital factor. Such cultural factors merit further exploration in understanding grief in adolescents with cancer, particularly in relation to family support.

The grieving adolescents in this study seldom sought help from peers in dealing with their grief. They assumed that peers without cancer could never understand their feelings and they shielded them from the grief they felt. And, because our participants knew that dark topics, such as death and dying, caused them to feel sad and uncomfortable, they knew that their cancer peers would have similar feelings. Consequently, they were reluctant to mention dark situations. As they did with their parents, participants tried to protect peers from darkness. Consequently, at times, participants found themselves feeling very much alone and isolated in struggling with a deeper darkness.

Our participants' avoidance of darkness showed that they were similar to healthy adolescents. Normally, adolescents in emotional jeopardy tend to avoid confronting and fighting through difficulties (McNamara, 2000). In a bereavement study, McNeil et al. (1991) noted that adolescents grieving over a friend's death used passive avoidance to hide their feelings, saying "I just wanted to be alone," or "I tried not to think about it," or "I wish people wouldn't dwell on it" (p. 138). Similarly, our participants kept silent and sought solitude to mask their grief. Indeed, feelings of darkness had persistently challenged our participants since the time of their diagnosis; seeking silence and solitude became long-standing coping strategies to deal with the darkness. Of interest, all participants were initially reluctant to mention, let alone discuss, their feelings of darkness. Over time, however, they seemed to welcome the opportunity for discussion with the first author. Long-term follow-up of our adolescent participants would be valuable to determine if this openness was only temporary and specific to certain non-family individuals.

Need for Further Research

Our data suggest that the avoidance of negative emotion and lack of open discussion about their concerns or fears served as an ongoing coping strategy for Korean adolescents with cancer. However, previous research indicates that this type of coping may be detrimental in the longer term. A common type of coping has been identified in adult cancer patients that is referred to as 'Type C" personality. These individuals tend to suppress their negative emotions, avoid emotionally disturbing issues, and refrain from discussions with others that may result in discomfort or potential conflicts (Zozulya, Gabaeva, Sokolov, Sorkina, & Kost, 2008). Unfortunately, this coping style has been associated with increased risk of developing cancer, cancer recurrence, and worse prognosis after treatment (Chida, Hamer, Wardle, & Steptoe, 2008; Lehto, Ojanen, Oyba, Aromaa, & Kellokumpu-Lehtinen, 2007). Results of this previous research raise concern regarding the health effects of avoidant coping patterns that our findings indicate are being used by Korean adolescents with cancer. Questions are also raised about how the adolescents’ avoidance, within the context of their culture, compares to that of Type C coping identified among non-Asian samples. Studies are needed to determine the relationship of these approaches to the ultimate well being of these adolescents.

Longitudinal studies of these and other adolescents could determine the effect of seeking silence and solitude to avoid darkness. For example, how do these specific coping patterns influence adolescents’ potential for growth through loss or their recovery from cancer? Does the ‘avoidance of darkness’ prevent their receiving support from others that could improve their cancer outcomes? How does cultural context influence the use of silence and solitude? In Korean culture, for example, silence is valued as a virtue; in American society, individuals are encouraged to openly share their emotions. How do coping strategies differ among cultures and how do they affect an adolescent’s maturation as an independent person? Do cultural expectations result in different relationships between avoidant coping and health outcomes? The answers to such questions will allow nurses to improve the grief support they give to adolescents who are struggling with darkness.

Clinical Implications

Our findings can lead to practical suggestions for nurses who care for Korean adolescents and, possibly, adolescents from other Asian cultures. Nursing interventions to facilitate coping may be important. Care plans for these individuals should (a) show respect for the cultural values of silence, solitude, and protection of parents from burden; (b) not force, or even suggest, open expression of darkness until a relationship with an adolescent has been established; (c) recognize that developing such a relationship proceeds slowly and takes time; thus assigning a primary nurse to any Asian patient to provide continuity is critical; (d) explore why adolescents engage in avoidance strategies; and (e) help other health care professionals to support grieving adolescents. Most importantly, nurses must consider that adolescents with cancer may be actively grieving and that Korean or other Asian adolescents are likely to hide the darkness they face.

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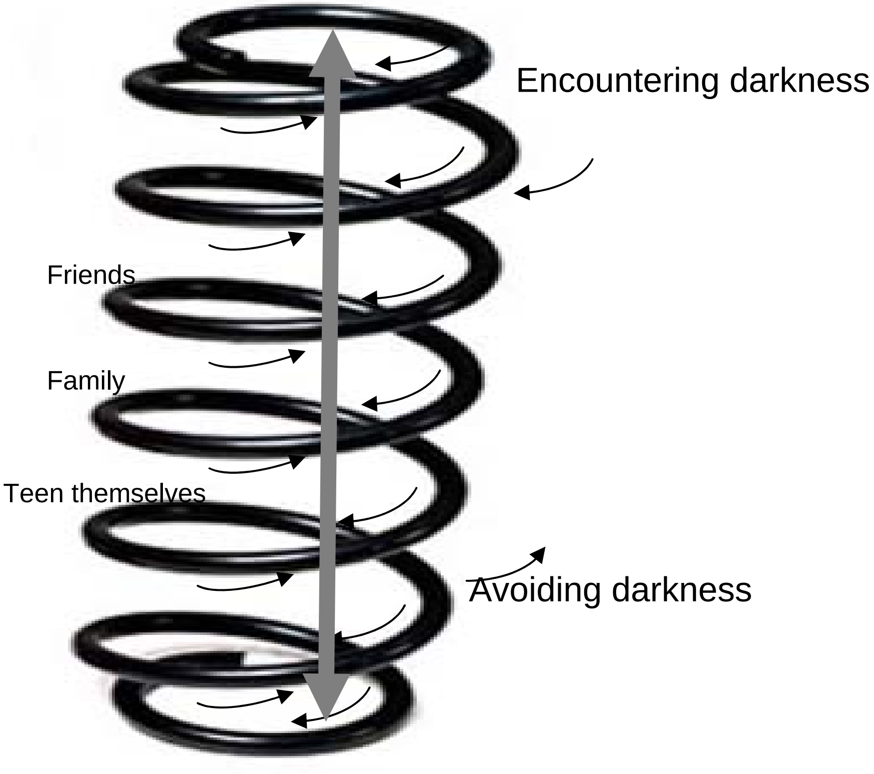
Figure 1. Spiraling in and out of darkness



CHAPTER 3.

FILIAL PIETY IN KOREAN ADOLESCENT CANCER SURVIVORS: EASING A MOTHER'S BURDEN

Title

Filial piety in Korean adolescent cancer survivors: Easing a mother's burden

Abstract

Background: Filial piety, respect for parents and ancestors, is commonly practiced by children and adolescents in Asian countries where Confucian ethics are valued. However, the concept of filial piety has seldom been incorporated into research studies, particularly from the perspective of young children or adolescents.

Objective: The aim of this article is to examine how the concept of filial piety permeates the attitudes and behaviors of Korean adolescents with cancer and their concerns for their parents, particularly their mother.

Methods: We designed a qualitative study that used a ground theory method. Fifteen Korean adolescents aged 13 to 23 years participated in the study. Data were collected by multiple methods: face-to-face interviews, telephone interviews, Internet chats, retrieval of personal Web journals, and observations of participants.

Findings: Korean adolescents with cancer tried to ease their mother's burden in these four ways: (1) for sons, by striving to meet parental expectations of carrying on the family lineage, (2) by hiding their own burden and appearing well and happy to lessen their mother's worry, (3) by reassuring their mother that they will return the care they received, and (4) by tactfully sensing their mother's feelings and thoughts.

Conclusion: Filial piety is a characteristic of adolescent-mother relationships in Asian families that may become more pronounced when a child has cancer, especially when he or she attempts to protect his or her mother and family members.

Keywords: Adolescent-parent relationships; Filial piety; Koreans

What is already known about the topic?

- Filial piety, a principal virtue of Confucianism, is interwoven into the daily lives of Koreans.
- Koreans and other Asians are less emotionally expressive than Westerners.

What this paper adds

- Conceptual components of filial piety are closely linked to the ways in which Korean adolescents with cancer make efforts to not show difficult feelings or emotions openly in front of their parents, especially mothers.
- Understanding the concept of filial piety and its impact on relationships between Korean adolescents with cancer and their mothers can enhance nurses' sensitivity to Asian cultural values and their ability to intervene in a culturally appropriate manner.

1. Introduction

Korean Confucianism emphasizes the fundamental importance of filial piety as a natural human response (Sorensen and Kim, 2004; Sung, 1998). For the most part, research on filial piety has studied the practice of filial respect and care of parents and elders in society as the duty and obligation of adult children (Sung, 1998). Little research has focused on younger children. However, the Confucian philosophy of filial piety still exerts a powerful influence on younger generations and shapes their attitude toward their parents.

Lún Yŭ, also known as *The Analects of Confucius, contains* the writings and sayings of Confucius (552 - 479 BC), the venerated Chinese thinker and philosopher (Confucius, 2007). This compendium primarily deals with individual morality and ethics and places a high priority on the value of family and social harmony. In the *Analects (Lún Yŭ)*, chapter 2, verse 6, Confucius says, “Avoid your parents’ having to worry about your well-being” (Confucius, 1999). Korean adolescents with cancer may feel the burden of this teaching, believing that they have failed to be good children. Obviously, this may negatively affect interactions with their parents. This article explores how Korean adolescent cancer survivors express the concept of filial piety.

2. Background: filial piety in Confucian culture

2.1. Confucianism and the relationship between parents and children

Central to Confucianism are five moral imperatives for interpersonal relationships which are collectively called *Oryun* in the Korean language. Oryun, which guides the foundation of proper relationships between human beings and humanness, includes (1) righteousness and justice between rulers and ministers, (2) cordiality and closeness between parents and children, (3) role differences between husband and wife, (4) order between elders and juniors, and (5) trust between friends (Connor, 2002; Molloy, 2004; Park and Chesla, 2007). Human relationships include moral codes that demonstrate how Confucianism stresses reciprocity or mutual responsibility. In the relationship between parents and children, parents are responsible for every aspect of their children's lives; in turn, children must be loyal and respectful toward their parents and care for them in their old age.

In a Korean family, the role of the oldest brother is unique and important because the societal preference for a male heir is still dominant. A first-born boy is regarded as the link between ancestors to descendants (Yi, 1993). Besides carrying on the family's lineage, a son enhances the family's social status and is expected to provide financial support for his parents in their old age. Consequently, a son's untimely death brings shame upon his family because he is considered an undutiful child since his death negates his ability to care for his parents as they age (Im, 2005). Because childhood cancer in Korea is about 30% more common in boys than girls, these beliefs become critically important in caring for male adolescents with cancer and their families (Ministry for Health and Welfare, 2005). The higher incidence of cancer is also directly related to the increased death rates for boys.

2.2. Filial piety in Confucianism

Filial piety (*Hyo,* 孝) means to love and respect one's parents, to make them comfortable, to bring them happiness, and to be a success in life ("The Classic of Filial Piety" as cited in Ebrey, 1993; Sung, 1997; Sung, 1998a; Sung, 1998b). Filial piety is rooted in *Oryun*, particularly pertaining to relationship between children and their parents. Following are the key conceptual constructs of filial piety.

2.2.1. Filial piety as respect, affection, and care

Caring for parents with respect and warmth is the foremost aspect of filial piety (Roetz, 1993). In doing so, children must cheerfully express their concern for the physical and spiritual well-being of their parents. In the *Analects*, chapter 2, verse 8, Confucius said, “Keep a reverential demeanor, though it is difficult to do” (Confucius, 1999). This saying, which suggests that presenting an unpleasant face to parents is not filial, might influence how Korean adolescents with cancer cope with difficult feelings, such as grief, in front of their parents.

2.2.2. Filial piety as fulfilling responsibility and obligation

Confucius said, “The body with its limbs, hair and skin comes to a person from his father and mother. It is on no account to be spoiled or injured” (“Teachings of Filial Piety” as cited in Sung, 1998). Because one’s body is perceived as a gift from parents, children should take care of their bodies throughout life until death. Besides showing their parents care and concern, filial children must reassure their parents that they themselves are safe, well, and healthy, so that they can maintain family continuity (Sung, 1998). Thus, for adolescent cancer survivors, having cancer means they are not being filially pious. Further, it is considered unnatural and extremely pitiful for parents to have to bury their own child.

Filial obligation also reaffirms the greatest debt that children owe their parents (Sung, 1998). Throughout the parents’ lifetime, particularly as they get older, children must give back the care they once received from them. Again, in repaying this care, filial piety directs that children should do so happily to make their parents feel comfortable.

2.2.3. Filial piety as promoting harmony in the family

Finally, filial piety emphasizes harmony within the family or the integrity of relationships between parents and children. In a harmonious family, children can fulfill their duties without misgivings (Roetz, 1993). In the Analects, chapter 4, verse 18, Confucius said, “In serving your father and mother, you may gently admonish them. But, if you see they have no intention of listening to you, then be respectful as before and do not disobey them. You might feel distressed but should never feel resentful” (Confucius, 2007). How parents feel and act supersedes the children’s feelings and actions. This focus on prioritizing parents and family needs over individual needs may negatively affect the attitudes and behaviors of children who encounter parental rigidity (Ho, 1995).

3. Aim

This article examines how the concept of filial piety helps one understand some of the central attitudes and behaviors of Korean adolescents with cancer and their concerns about their parents, particularly their mother. The data presented here were collected by the first author as part of her dissertation, “Encountering Darkness: Grieving in Korean Adolescents with Cancer.” Although filial piety was not part of the original conceptualization of the study, the data analysis suggested its pivotal role and guided exploration of the concept in later interviews. The first author, herself a Korean, recognized that the concept was pervasive throughout the data.

4. Methods

4.1. Design

The original qualitative study used grounded theory to explore the experience of grief in Korean adolescents with cancer following the deaths of friends to the same illness. The grounded theory method explores the process by which reality is socially constructed (Charmaz, 2000, Strauss and Corbin, 1990). The process is based on the idea that people reveal several ways of "being" in their social world, constituting their interactions with others. Grounded theory moves beyond the theoretical or conceptual frameworks that show a sequence or causality, implying a beginning and an end or a condition and a consequence (Strauss, 1987). As such, Korean adolescents who survive cancer move through phases (e.g., from in-treatment survivor to post-treatment survivor, from 2-year, off-treatment survivor to 5-year, off-treatment survivor), and they encounter new situations that reshape and are shaped by interactions within social structures.

The key social process can be found by exploring how people share their problems and resolve or ameliorate them within their realities (Schreiber, 2001). Thus, in uncovering the grieving experiences of Korean adolescents with cancers, it was crucial to examine how they confronted the challenges of cancer-related losses and to explore the patterns of their associations with people during their problem-solving experiences from illness to survival.

4.2. Participants and data collection

Data were collected from 15 Korean adolescents who registered at a university-affiliated hospital in Seoul, Korea (13 males and 2 females). At the first interview, the age of adolescents ranged from 13 to 19. Upon completion of the study, the oldest participant was 23. The participants had been diagnosed with a cancer and were less than 5 years into complete remission. They regularly visited the hospital or its outpatient clinic for follow-up care every 3 or 6 months. Many of them participated in a self-help group that regularly met in the hospital and had their own Internet homepage. Each adolescent participated in at least 2 of the following types of interviews, for a total of 9 face-to-face interviews, 4 telephone interviews, 17 Internet chats, 2 observations of the social dynamics of participants within self-help groups, and 5 retrievals of personal Web journals. Initial interview questions included “Tell me about yourself and your family,” “Tell me about your relationships with your parents since you became ill with cancer,” and “Tell me about any family situations that made you sad.”

4.3. Data analysis

Analysis of the data began by coding the data and writing memos. Concurrent and integrative collection, analysis, and conceptual theorizing about data were done systematically. The first step of textual analysis began by studying transcriptions of interviews and field notes to code with labels from the data. From this initial labeling, the authors created progressively more abstract conceptual categories that explained what the data indicated, constantly comparing the categories to ensure that they were mutually exclusive. The authors also wrote memos to preserve analytic decisions, emerging hypotheses, hunches, questions, and reflexive ideas. Memos make *abductive reasoning* possible, allowing a researcher to draw out possible abstractions by moving back and forth between data and ideas (Atkinson et al., 2003). Theoretical memos were written as narrative analyses to compare and contrast evolving codes and categories, and to draft parts of the initial analysis. This process helps the researcher to direct and shape the emerging analysis (Charmaz, 2003). To ensure rigor, more than one author examined codes, categories, and analytic memos. Agreement regarding meaning of the data occurred through a series of meetings among the authors.

5. Findings

The findings of the original study show that Korean adolescents with cancer grieved for more than just the loss of peers who had cancer. A friend's death was just one of many reminders of the pervasive grief they had experienced throughout their illness and recovery and still experienced in daily life. Central to the adolescents' experience was their concern for and behavior around their family, particularly their mother. Despite the adolescents' emotional distress regarding their own illness, consideration of their parents, especially their mother, came first. As primary caregivers, selflessly committed to their child's needs, mothers were held in the highest regard. Although, many participants did not have an intimate relationship with their fathers, they respected their fathers for financially supporting the family and knew that they were still loved by their fathers. Because the mothers of the participants spent the most time with the children during the cancer treatment process, when talking about parents, most participants answered questions with regard to their mothers. Thus in our paper, we examined the concept of filial piety with regard to the relationship between the participant and their mothers. In the discussion that follows, we examine how the adolescents tried to lighten their mothers' burden and how their attitudes and actions were rooted in filial piety.

5.1. Being concerned about infertility: "Would it be possible to be a dad?"

In previous studies, young adult cancer survivors often worried about their reproductive ability (Zebrack et al., 2004). Korean adolescents with cancer shared this concern, and young men in particular were acutely aware of their responsibility to carry on the family lineage. In their view, surviving cancer was not enough to please their parents. Participants grieved over the loss of their potential infertility. As one 18-year-old male participant lamented:

> I received several series of radiation therapy over my belly. I have been always concerned that it might affect fertility, although my doctor said that would not happen to me. As you know, I am the only boy in my family. If I fail to have a child, I don't want to imagine but, I would feel very guilty and sorry towards my parents.

5.2 Bearing my own burden: "I am doing okay, mom. Don't worry."

Participants felt apologetic about the care and aid they received from their parents during recurrent hospital admissions. They had observed how demanding it was, both physically and emotionally, for their parents, especially their mother, to be caregivers. As a result, the adolescents behaved as if everything was fine, even when they encountered difficulties. They were reluctant to share their concerns or worries with their mother, even when they felt ill or wanted to talk about their problems. Characteristically, the adolescents repressed their grief in a manner that would not burden their parents, especially their mother who stayed with them during their frequent and often lengthy hospital admissions (Sato et al., 2005, Stevens and Dunsmore, 1996). A 19-year-old female participant explained,

> I really don't want my mom to see me cry. I need to be stronger in front of her. If she sees me cry, she would become sad too. She has dealt with so many difficulties already. I do not want to hurt her anymore.

An 18-year-old male participant concurred,

> I know that my family is always worrying about me. I don't want to be a burden to them anymore. That's why I have been saying "I'm okay." But actually, many times, I was not okay.

The participants wanted to make their families as happy as possible. Although their cancer experience permeates their present life and adolescents and their parents realized the risk of cancer recurrence, the adolescents were adamant that they did not want to be the center of family concern. To create a happy family atmosphere, participants disguised their emotional distress and acted as if they were doing well.

5.3 Paying back mothers: "I will make my mom pleased with me."

Having survived cancer, participants were acutely aware of their parents' extraordinary care, especially their mother's, and their obligation to repay that care and attention. Participants worked extremely hard during and after completion of treatment to do their absolute best in all endeavors, especially in preparing for university or college. An 18-year-old male participant said, "I know my mom will be very pleased if I study harder and go to a good university."

Participants rued the heavy financial burden of their cancer treatment, remembering how often their parents felt distress in paying medical bills. The adolescents suffered from chronic feelings of guilt, a covert grief that lingered throughout their family's financial difficulties. These financial losses were part of the debt participants wanted to repay to their parents. A 17-year-old male participant remarked,

> I need to be healthy so I can take care of my parents, and make big money to clear debts my family incurred because of my illness. You can not imagine how many times I wanted to say "I will make you rich, mom" while I was hospitalized.

5.4 Using *noonchi*: "I can read my mom's mind."

Within their largely homogeneous culture, Koreans are often skilled at indirect communication, called *noonchi* in the Korean language (Cha, 1994). People with noonchi, the ability “to read between the lines,” are sensitive to contextual cues, and quickly grasp subtle nuances upon which they determine their most appropriate responses. In ideal interactions, Koreans do not have to express their inner thoughts and feelings in explicit and detailed ways because they believe that sincere intention is conveyed by *e-sim-jeon-sim*, a term that means *from one mind to another*. As such, participants relied on noonchi to judge, assess, or determine if they could openly show their emotions and feelings to their mother. Undoubtedly, the adolescents deferred to their mother’s expectations. They seemed to regard noonchi as an adequate and necessary strategy when interacting with their mother. An 18-year-old male participant confided,

> I knew everything that went on even if my mom did not tell me anything. I could read her face and her behaviors. I didn’t have to ask. Because, I bet, she would have been very shocked to know that I already knew it [the death of my friend].”

Individuals who practice filial piety need to be introspective and morally vigilant (Roetz, 1993) about harmony within the family. For example, by using noonchi, our Korean adolescent participants remained sensitive to the feelings of all family members. For some adolescents, the closer they felt to their mother, the more they felt sorry for their siblings. Their mothers remained overprotective of them, even as cancer survivors, and by comparison paid less attention to their siblings. Consequently, the adolescents often pondered how they could repay their mother. And, they felt indebted to their siblings for the parental attention that they did not receive. A 15-year-old male participant stated,

> One summer day, I remember my older sister had food poisoning. She had eaten something from home that had gone bad. Since my mom was taking care of me

> all the time, she didn’t have time to care for my sister and for her meals. I felt bad that my sister was in her senior year of high school and preparing for her college entrance exams, and that my mom couldn’t be there to support and care for her because of me. You know, many Korean mothers obsess over getting their children prepared for entrance exams. My poor sister had to take care of herself on her own.

In summary, Korean adolescents with cancer expressed filial piety toward their mother in four ways: (1) for sons, by meeting parental expectations of carrying on the family lineage, (2) by appearing well and happy to lessen their mother’s worry, (3) by reassuring their mother that they will return the care received, and (4) by tactfully sensing their mother’s feelings and thoughts.

6. Discussion and Conclusion

Adolescents typically spend less time with parents or family and increasing amounts of time with peers as they approach adulthood (Larson et al., 1996); adolescent-parent relationships evolve from dependence to separation (Harter, 1990). For adolescents with cancer, these developmental transitions can be difficult because the trajectory of their chronic illness leads them to be more concerned about family relationships than interactions with peers (Banner et al., 1996). And, even when a son or daughter has been cancer-free for several years, complete independence seems more difficult because parents would not allow their children to leave the house and continue to worry about their children’s health. However, the authors do not consider filial piety to be a constraint in Korean adolescent-parent relationships but rather a means of understanding the interdependence between adolescents and their parents.

Korean adolescents with cancer made extensive efforts to avoid burdening their mother or adding to her emotional pain. During the course of their entire illness, the adolescents experienced ongoing losses (e.g., loss of hair, loss of friends with cancer), but were always reticent to express their inner feelings such as sadness, frustration or loneliness. When questioned in subsequent interviews, adolescents regarded filial piety as a taken for granted, assumed duty. Indeed, the duty they discussed was one of the theoretical constructs of filial piety, fulfilling responsibility or obligation (See Table 1). The other two constructs of filial piety can only be observed by a third party, not through admission by the participants themselves, because only an older individual can determine if a younger subordinate is filially pious. Since the adolescents took for granted filial piety as a duty, burdens stemming from their practice of filial piety remain, which we need to pay attention to.

In caring for Chinese, Japanese, or Korean adolescents, nurses should be aware that filial piety is a core cultural value that affects the adolescents’ interactions with their parents and family as a whole. And, they must be sensitive to the possibility that those who put on a brave front are attempting to lighten their mother’s burden. Although discussing the concept of filial piety directly with adolescents may not be effective if youth do not recognize its influence in their lives, or if they believe that other factors are at work in shaping their family dynamics and communications, nurses should recognize and value their efforts to protect their mothers and family members, and encourage them to share their thoughts and emotions with others outside of the family. Filial piety is a Confucian virtue that is deeply embedded in Asian culture, one that cannot be modified or treated, a quality of adolescent-mother relationships in Asian families that becomes more pronounced when a child has cancer.

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Table 1. Conceptual links between the theoretical constructs of filial piety and findings

Theoretical constructs of filial piety	**Findings**
Respect, affection, & care	Bearing the burden stoically – by appearing well and happy in front of parents, avoiding complaints
Fulfilling responsibility & obligation	Paying back & meeting parental expectations – by reassuring parents that the adolescents are safe, well, and healthy, and will fulfill future obligations
Promoting harmony in the family	Using *noonchi* – by tactfully sensing mother's feelings (How parents feel and act supersedes the adolescents' feelings and actions.)

CHAPTER 4.

CULTURAL CONSIDERATIONS IN CONDUCTING QUALITATIVE RESEARCH WITH KOREAN ADOLESCENTS WITH CANCER

Title

Cultural Considerations in Conducting Qualitative Research with Korean Adolescents with Cancer

Abstract

Aim: The aim of this paper is to describe the influence of Asian, particularly Korean, culture on the conduct of qualitative research.

Background: Despite recent qualitative studies on adolescents with cancer, little is known about the research process and the methodological challenges of working with Asian or Korean adolescents with cancer.

Method: A grounded theory study was conducted of 15 Korean adolescents with cancer aged 13 to 23. The data were collected in face-to-face interviews, telephone interviews, Internet chats, and retrieval of Web-based materials between March 2008 and March 2009.

Findings: Cultural influence on methods, particularly focusing on participant recruitment and collecting data, is examined in the relevant areas, which are hospital-based recruitment, multiple methods of data collection, and relationship between participants and researcher.

Conclusion: Cultural considerations that are taken into account in this article give invaluable insights on future qualitative research in collecting data from ethnic groups holding a Confucian/collectivistic cultural orientation.

Keywords: Korean, Asian, culture, Confucianism, collectivism, qualitative research, data collection, telephone interviews, internet data collection

Summary Statement

What is already known on this topic:

- Qualitative research on Asian adolescents with cancer is minimal.
- Confucianism and collectivism are the main cultural ethos in Asia.

What this study adds:

- An analysis of how Asian and Korean culture affects data collection for a qualitative study and a description of the successful methodological practices used.
- Culturally appropriate strategies for nurse researchers when recruiting patients and families who live in a collectivist society.

Implications for practice and policy:

- Understanding a family-like gatekeeper group is essential when recruiting Asian or Korean adolescents to participate in a research study.
- Nurses caring for Asian or Korean adolescents need to establish a trust-based relationship and maintain it.

Recent qualitative studies of adolescents with cancer have provided a burgeoning source of knowledge about this population (Brown, Pikler, Lavish, Keune, & Hutto, 2008; Carlsson, Kihlgren, & Sorlie, 2008; Cassano, Nagel, & O'Mara, 2008; Chen, Chen, & Haase, 2008; Drew, 2007; Gallo, 2003; Hokkanen, Eriksson, Ahonen, & Salantera, 2004; Kelly, Pearce, & Mulhall, 2004; Larouche & Chin-Peuckert, 2006; Wilkinson, 2003; Woodgate, 2005). However, none of these studies have focused on an Asian population. Little research worldwide has studied Asian adolescents with cancer (Chen et al., 2008; Papadopoulos, Guo, Lees, & Ridge, 2007; Yeh, 2002). And, little has been done to investigate the qualitative research process or methodological issues that are particularly relevant when working with Korean or Asian adolescents with cancer.

The paucity of scientific studies might reflect the challenge of conducting qualitative research in Asian countries where the quantitative paradigm still predominates. Indeed, Asians are more accustomed to answering multiple-choice questions than open-ended questions. More important, in a Confucian culture where sharing personal thoughts and feelings is not the norm and being reticent is a good quality (Confucius, 2003; Kim, 1995), people are more hesitant than Westerners to express thoughts on sensitive issues or taboo topics. For example, Asians believe that mentioning death or death-related topics brings bad luck to one’s family. Thus, researchers, particularly those who are Asian, may find it difficult to conduct qualitative interviews that require in-depth exploration of feelings and thoughts about death or other sensitive topics.

The cultural orientation to collectivism in Asian countries must also be considered. Collectivist cultural traditions are characterized by a set of values that include obedience to authority, embrace group-oriented interdependence, put a high priority on the goals of in-groups (i.e., family and community), act in a communal way, and are concerned with maintaining harmonious relationships with others (Englehart, 2000; Triandis, 2001). Consequently, researchers seeking to collect data from groups in collectivist societies must anticipate potential pitfalls and use culturally appropriate research strategies that respect these collectivist values.

In this article, we discuss our experience in conducting a qualitative study of Korean adolescents with cancer in light of these two principles of Asian culture, Confucianism and collectivism. A brief description of the study follows.

Background of the Study

A qualitative study using grounded theory was conducted to explore the experience of grief in Korean adolescents with cancer following the deaths of friends to cancer. Data were obtained from a Korean population aged 13 to 23 ($N = 15$) through face-to-face interviews, telephone interviews, Internet chats, observations of the social dynamics of participants within self-help groups, emails, and retrieval of personal Web journals between March 2008 and March 2009. The first author, herself a Korean, collected all of the data and translated the Korean into English. In the following discussion, we specifically address three issues relevant to culture: hospital-based recruitment, multiple methods of data collection, and the relationship between participants and researcher.

Hospital-Based Recruitment

Knowing and acclimating to a setting is the first step in establishing the effectiveness of a study. *Setting* does not necessarily mean a fixed place; it can also indicate people living in a particular social situation that includes one or more physical locations and the perspectives and memories evoked there. In our study, the hospital where participants were treated was the main physical setting, although they had often completed treatments and left the medical environment. Potential adolescent participants came to the hospital to receive follow-up medical care and to socialize with their cancer mates, with whom they had received treatment. The hospital also played an important role as a site for face-to-face interviews. For the participants, it evoked powerful memories of their illness, past treatments, and losses.

Above all, the hospital was *the* site where the key gatekeepers (i.e., pediatric oncologists, the mothers' group, and youth volunteers or coordinators for self-help groups for adolescents with cancer) were located. These three key groups were instrumental in recruiting participants and were integral to the study process from the beginning. Within the gatekeepers' protective network, the adolescent participants, their families, and the gatekeepers developed an ongoing, family-like relationship. To recruit adolescents for our study, we needed the gatekeepers' support.

Customarily, a researcher who wishes to recruit patients in a hospital requires their physician's permission. Since institutional review boards in the major university-affiliated hospitals in Korea have been established, this requirement is less demanding. However, the involvement and goodwill of physicians is still powerful. In our study, the first author invited one of the hospital's chief pediatric oncologists to serve as a member of her master's thesis committee. In subsequent years, while volunteering for various projects involving the pediatric oncology population, the first author maintained close contact with the oncologist. Thus, he was willing to assist in the recruitment of adolescent participants and their mothers. Posting flyers in and around the oncologist's hospital office proved to be more effective than mailing recruitment letters to potential participants. However, the oncologist's direct request of his adolescent patients and their mothers to read the flyers during their regular check-ups proved to be one of the most effective recruitment strategies. He obviously evoked the traditional Korean paternal image among his patients and their families. Because Korean family members are required to obey and to abide by their father's decisions, adolescents and their mothers showed more interest in participating in the study after the oncologist discussed it with them. To avoid any semblance of coercion, all participants were informed that their participation was completely voluntary, and, if they declined to participate, their medical care would continue as usual. Nevertheless, the oncologist's endorsement of the study was invaluable in recruiting participants.

Conducting our study in the hospital also required that we become familiar with the participants' mothers. They often came to the hospital just to meet other mothers in the outpatient clinic or the in-patient units where they had met other mothers and their ill children during prior admissions. As a group, the mothers wanted to know everything that was going on in the hospital with other adolescents with cancer, even though their child may not have been eligible for the study. For example, they shared information on who joined the study and who did not and why, what possible questions the study participants would be asked, and if their physician was supporting the study. Consequently, before data collection began, the principal investigator (PI; the first author) explained the study to a few key leaders among the mothers so that they could answer questions from other mothers. These leaders, rather than the researcher or the local institutional review board, proved to be the primary source of information for mothers interested in the study. Regarding privacy and confidentiality, the researcher reassured the mothers that she would not divulge any personal information that their children disclosed, and she explained the importance of ensuring participants' privacy in terms of adolescent development.

Youth volunteers or coordinators (i.e., university student volunteers at the affiliated hospital or young adult cancer survivors), the third group of gatekeepers, were also important. These young people demonstrated their support for children and adolescents with cancer by spending time with them at hospital events or regular activities. The adolescents with cancer regarded them as older sisters or brothers or trusted friends. The youth volunteers were instrumental in permitting us to observe self-help group activities. Just as the children or adolescents were attached to their parents, the adolescent group members felt secure with the youth volunteers. Thus, the researcher had to be well-acquainted with the volunteers so that they would give her a favorable introduction to the adolescents. And, the volunteer gatekeepers informed the researcher about the adolescents' personalities, their levels of activity in the group, and insights about their families and friends. These reports were incorporated into field notes or memos.

Multiple Methods of Data Collection

With the gatekeepers' invaluable assistance in recruiting participants, we proceeded to data collection. Participants selected their preferred type(s) of interviews and other means of data collection: face-to-face interviews, telephone interviews, Internet chats, and retrieving Web materials. The interview options were designed to foster not only more participant autonomy but also ongoing communication between the participants and the researcher, who was most often geographically distant (Sturges & Hanrahan, 2004).

General Data Collection Strategies

Because most of the participants' interviews had to be informal in order to build rapport, they strayed from the planned questions. During the first face-to-face interview, participants needed time to get to know and trust the researcher with their innermost thoughts. The second or the third interviews then proceeded more smoothly, with semi-structured questions based on the topics or phrases mentioned in the first interview.

The researcher found that one of the most effective ways to establish rapport with participants was to answer their questions. For example, participants were eager to learn how the researcher arranged to study abroad. Throughout the study, they were interested in knowing about her progress. Of the four data collection methods, interviewing participants online through Internet chats was particularly well-suited to the Korean youth culture, and it respected their usual communication habits. The unique value of each interview method follows.

Face-to-face interviews. One-on-one interviews had two strengths, which led us to use this method for most first contacts with participants. First, following initial conversation and establishing rapport, consent forms were signed. Second, the researcher could observe directly how adolescent interviewees responded to the questions. Interpreting an interviewee's subtle responses was possible, allowing the interviewer to encourage the interviewee to articulate his or her experiences. Asking questions with appropriate phrases and words adapted for Korean youth and developing a trusting relationship were the key issues that we faced during the first face-to-face interviews.

The first one-on-one interview focused on narratives about the participants' bereavement experiences. The researcher began the interview with this invitation: "I would like to know about a situation where your friend with cancer died. Tell me a story about deaths from cancer you experienced since you were diagnosed with the illness." However, we learned that this topic could not be addressed at the beginning of the interview. Most adolescent participants had seemed dismayed by the mention of death, however brief, when the study's description was described to them and when they signed their consent form. Because death is usually not discussed in Korean culture, such frank questions had to be broached only after a level of trust between the participant and the researcher had been established. Accordingly, we first asked participants about their personal histories, their friends, and their families. Although commonly used in qualitative research in Western cultures, the request, Tell me your story about…, was ineffective. Adolescents responded: "I am not much good at talking to people," "Story? What does it mean? I do not have a story," or "Do you want to examine something inside of me?" Participants responded better to specific questions or rephrased questions. Thus, open-ended requests, such as "Tell me about cancer you experienced" or "Tell me about your friends with cancer", had to be combined with more structured questions to elicit fluid responses and to encourage the adolescent participants to talk about their experiences.

Participants were curious to know what their cancer peers told the researcher. Thus, we found it helpful to frame questions within this broader familiar context: One of your friends mentioned that something [topics or phrase] was important to them. How do you think about what he/she said? Phrases or symbols used in naming their Internet homepage were helpful in stimulating conversation during the initial interview. Topics or issues that participants stated in their Web journals, which were publicly accessible, also elicited reflections on their past cancer experiences and their current lives. Participants enthusiastically discussed their school achievements or time spent with their friends, but somberly described topics that upset them, such as family conflicts, loss experiences, and past illness experiences. They often dropped their head or avoided the interviewer's gaze when discussing the latter, leading them to choose indirect conversations as detailed below.

Telephone interviews. The telephone interview raises a crucial concern: non-visual communication between researcher and participant. In other words, a researcher cannot observe what a participant does during an interview and cannot interpret his or her non-verbal communication. A few of our telephone interviews did not go well because participants, talking on their cell phones and distracted by other activities, were not focused on their conversation with the interviewer. At times, such interruptions caused interviews to be terminated early. The researcher then tried to reschedule a telephone interview from a participant's home where he or she could be alone. This improved the attention span for some participants. Other participants divided their attention between the Internet and the telephone interview. Although this negative aspect of telephone interviews is well-known in qualitative research (McCoyd & Kerson, 2006; Opdenakker, 2006), it illustrates how typical adolescents use electronic devices simultaneously (Strasburger, Wilson, & Jordan, 2008).

The telephone interview, however, had a distinct advantage over a face-to-face interview: participants found it easier to discuss difficult issues. A participant who wanted to hide his surging emotions stated at the end of the interview, “I almost burst into tears at one point, but I felt okay because you couldn’t see my face during that moment. It would be very hard for me to manage not to do it if we were meeting face to face.” Despite their merit, telephone interviews were often replaced with Internet chat, the most common way in which Korean adolescents communicate.

Internet chats. Communicating online with friends allowed adolescents to feel comfortable. No published data report what percent of Korean adolescents with cancer use instant messaging to communicate with others. But, Internet chat is embedded in the adolescents’ everyday routine as a way of connecting with their peers, those with and without cancer (Hinds, Burghen, Haase, & Phillips, 2006).

Initially, we planned on using Internet chats to maintain rapport with participants; we did not expect to obtain detailed conversations. However, Internet chats became a very useful means of collecting data from Korean adolescents. The researcher and participants were able to discuss topics in depth, so much so that they often lost track of the length of their conversations, which sometimes lasted up to 3 hours. In using Internet chats versus face-to-face interviews, participants viewed the researcher as less of an authority figure. One of the participants explained, “You (the interviewer) are like one of my Web-buddies.” The technological advantage of the auto-save feature was an exceptional help to the researcher, allowing the researcher or participant to paste the saved text to a word document to review a conversation. Of course, the researcher and participants could revisit their questions and answers from previous conversations.

Furthermore, as long as participants and the researcher agreed, both could switch to a voice-chat or a Webcam-chat while using instant messaging.

Internet chats, however, raised some worrisome concerns, the biggest of which was the Korean adolescents' language. The PI, although herself a Korean, had to learn the contemporary trend of adolescent Web communication that includes an extensive variety of abbreviated new words or phrases, emoticons and graphics. To avoid interrupting participants by asking what their abbreviations meant, the PI chose not to ask participants to refrain from using the abbreviations, particularly word abbreviations. And, she found their use of emoticons that denote feelings or emotions to be very helpful because expressing emotions verbally is atypical. Learning the participants' Internet language required some effort, but it was worthwhile in building relationships because participants seemed very proud and glad to teach the researcher their language. Despite the initial knowledge gap between the researcher and participants, the researcher found Internet chats to be a more rewarding experience than other forms of interviewing.

Internet chats also precluded time for being reflexive. Because a chat involves rapid-fire exchange, it could not be used to collect data on a one-time basis or be used as a first interview. Rather its most appropriate use was to complement other data collection methods. For example, before an Internet chat, the researcher communicated with a participant by email to elicit his answers to a few key questions about his cancer experience. Although his email answers were short as expected, they contained words, phrases, and even symbolic messages that the researcher used in writing a reflexive memo, which provided her with specific probing questions for the next scheduled chat.

Finally, the PI was concerned that participants might view multiple Internet chats as being intrusive. Her presence, indicated by the “logged on” sign in the chat room, might be burdensome to participants, especially if one wanted to drop out of the study. To avoid interruption, participants often indicated that they were “busy,” “away,” or “offline”. But, such refusals to participate did not necessarily mean that they wanted to drop out of the study. After some time, they would log on again, greet the researcher, and query her about the other participants’ conversations and recent events in the researcher’s life. We viewed the participants’ informality and control of communication to be a developmentally appropriate feature, revealing their negotiation skill in communicating with others and expressing themselves online. Sometimes, this informality led to delayed or missed scheduled Internet chats, causing the interviewer to waste a lot of time waiting for them. Participants seemed to regard chat appointments as casually as they did instant messaging their friends. Sooner or later they came back on the Web and wanted to resume a conversation with the interviewer if she was logged on, or they sent an instant text message of apology. For the researcher, then, using instant messaging throughout the project was a challenge: Sometimes it was a vehicle for a formal interview, at others times it was a way to build rapport with participants.

Retrieving data from Web homepages. Korean adolescents commonly have their own Internet homepages, called “Mini-hompi,” or “Cyworld.” Web texts allowed the researcher to read the concerns that they had shared with the public (mostly their friends), to see the exchange of communication among them, and to analyze how these non-face-to-face interactions were shaped by the Web. The researcher and participants mutually agreed to use selected functions, such as diaries and visitors’ logs. The researcher first asked participants to retrieve their previous and current public diaries, which many allowed. The researcher also asked them to write journal entries whenever they were reminded of a difficult experience, thinking that those documents could be disclosed to the public and sent to her by email. However, none of the participants wrote these additional journal entries. Seemingly, participants felt burdened to write something especially for the study. Instead, they preferred using the visitors' log, which afforded the researcher and the participants secure communication. Additional questions were asked and answered using this function. Characteristically, the Web data concerned the participants' feelings or emotions on a specific day or an event that involved interacting with others. Their short written accounts of their feelings and emotions served to initiate a subsequent interview or offered entrée to further explore their experiences.

Relationship between Participants and Researcher

Data collection forged a special relationship between participants and researcher. On completing each interview, participants acted with considerable thoughtfulness, suggesting to the researcher many sources of additional data, such as secrets in their diaries, and they explicitly noted that they wanted to maintain contact with the researcher via the Internet. More than their specific words or narratives, the participants' openness to bare their innermost thoughts and feelings throughout the study was the most rewarding outcome for the PI. The participants' openness seemed to be rooted in *jeong*, which is a unique emotion embedded in Korean culture (Kim & Ryu, 2005). It has no counterpart in English and is somewhat difficult to define even in the Korean language. Korean-English dictionaries define jeong as feeling, love, sentiment, passion, human nature, sympathy, heart, and the like. During this study, we came to realize that the interpersonal attachment, the bond between participant and researcher created by spending significant time together, allowed jeong to form. In Korean culture, jeong creates a tight connection between people allowing them to work together to resolve tensions and concerns, thereby narrowing the usual gap between two individuals and creating a sense of shared purpose.

Of course, at first, participants were wary that the researcher might be another parent-like adult. After participants recognized that the researcher could be like one of their youth volunteers, with whom they could talk openly, the relationship between them and the researcher strengthened with jeong. Interestingly, those who dropped out of the study (n=2) and those who withheld their feelings or thoughts during interviews, also had jeong toward the researcher. Thus, regardless of the depth of openness between participants and researcher, participants wanted the researcher to keep them informed about the study's progress and offered to help her in any way they could. In Korea, helping one another is highly valued. For example, in return for the help participants had received as inpatients, they agreed to participate in both their physician's and the PI's study. This reciprocal relationship, based on jeong, created a dilemma for the researcher when the time came to end her relationship with the participants. The jeong engendered during the study implied a longer term commitment, one that would normally be expected to continue in within Korean collectivist society. To honor this cultural commitment, the PI had to shift her focus from the research project to a more general acquaintance and to leave open the possibility of working with the participants on a future research project.

Discussion

In reflecting on Asian culture and its impact on participant recruitment and data collection in qualitative research, we noted several collectivist aspects. The key gatekeepers in the hospital formed a family-like or synchronized group. Adolescent participants were also vigilantly concerned with each other. For example, when a participant queried “How did others answer the question?” he or she expected to answer the same questions that cancer mates had been asked. Thus, the researcher had to share other participants’ answers in a general way (without compromising confidentiality) to entice other participants to respond. Often, participants actively conversed with the researcher only after hearing others’ responses. Although interviews were conducted individually, the process of obtaining answers about cancer experience reflected how the Korean adolescent participants were interdependent among each other. The collectivist aspects of Korean culture and the shared experience of illness put the focus on the group rather than on the individual.

Maintaining a relationship between participants and the researcher was more important than just establishing the relationship. The relationship was a process of developing group harmony, a feature of collectivist culture (Rarick, 2007). It was to be gradual, mutually constructive, and conflict-free for all. Thus, communication via Internet chats was the most useful strategy because it allowed frequent conversations and provided continuity over time. Most important, the online chats helped the researcher to maintain a friend-like relationship with the adolescent participants; this made them feel comfortable and talk more openly. And, online chats allowed jeong, a strong bond-like affection, to develop between the researcher and participants. Ultimately, this led us to conclude that the adolescent participants’ initial reluctance to discuss taboo topics was not solely because of the subject matter but the absence of a trusting relationship that allowed the parties to interact without tension.

Where jeong is involved, managing relationships with study participants can be problematic. To Western researchers, jeong might be considered “emotional baggage” for Asian or Korean researchers. A researcher may find it burdensome to terminate research relationships while maintaining the reciprocal obligations implied by jeong. However, understanding and adhering to jeong helped this researcher enter the adolescents’ world, as members of Korean society and as study participants. Ending the research relationship, while finding other ways to maintain cultural obligations, was a challenge that demanded our sensitivity, tact, and willingness to go beyond the standard boundaries of research.

Implications for Future Research

This study’s findings suggest areas for future research. First, the concept of gatekeeping must be better understood. Individuals with any chronic illness requiring a long-term care-giving commitment to both patients and their family members can provide the context for further studying the nature of gate-keeping. In particular, non-family members must be considered potential gatekeepers, particularly for adolescents who have many relationships beyond their immediate family. Second, culturally-specific factors that affect gatekeeping must also be investigated. Many of the world’s people, including African Americans, Hispanics, Jews, and Arabs, hold collectivist values (Chan, 2005; Maydan, Nicotera, & Clinkscales, 2003; Sagy, Orr, Bar-On, & Awwad, 2001). Thus, nurses must seek out and use culturally appropriate ways to approach patients and families who live in a collectivist society. Finally, gaining a greater understanding and appreciation of culture-specific beliefs and practices would help create culturally appropriate research. Studies such as this one should be conducted with these considerations in mind.

Conclusion

In this article, we examined how Asian or Korean culture can affect qualitative research, particularly in recruiting and collecting data from adolescents. Understanding how the Confucian/collectivistic cultural orientation values harmonious relationships is crucial in approaching a population strongly influenced by collectivism. This study should offer future researchers invaluable insights in working not only with other Asian adolescents but also any population in a collectivist society.

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CHAPTER 5.

CONCLUSION

Grieving as the Process of Adapting to Losses

> … Over time, moments, then hours, even days of relative happiness penetrate the pervasive darkness. A balance between sorrow and joy begins to emerge in our lives. Even these most familiar parts of our worlds may at times still arouse pain and anguish as fresh memories and associations surface. But the intensity is rarely as great or long lasting. We can and do relearn how to be and act at home and at ease, in ways old and new, in the worlds we experience (Attig, 2000, p. 13).

The quote above best describes the experiences of the participants in this study. My starting focus, the grief of Korean adolescents with cancer following the death of their cancer peers was just one source of darkness for the participants. Their experience with cancer, with all of its trials and tribulations, provided additional sources of darkness and impacted upon them in relation to their friends and family members. Since the time of their original cancer diagnosis, the adolescents experienced both happy and unhappy moments. However, they responded to the darkness by seeking joy and “normal lives” with their friends, with both those who had cancer and those who did not. They also faced difficult challenges of feeling burdened themselves and concern for the burden their illness imposed upon their families. Their darkness included various emotional predicaments resulting from distress about mortality. And, still, the adolescents found ways to adapt to and cope with the darkness (Chapter 2). They strove to live harmoniously with others within their internalized cultural values, as illustrated by filial piety (Chapter 3). Since they had observed their mother’s suffering in the past, since the time of their own diagnosis of cancer, they anticipated their mother’s ongoing difficulties and put their own feelings aside to make efforts to do their best to please their mothers as well as to protect them from the extra emotional burden that would result if the adolescents shared their darkness with her. The adolescents' adaptations were also shown in how they finally opened up their emotions to the researcher through multiple ways of interacting with her (Chapter 4). Initially, the researcher was another reminder of the darkness, and the participants wanted to avoid discussion of the darkness with her. But, over time, and with patience, the researcher engendered their trust and they, sometimes for the first time with anyone, opened up and shared their experiences of darkness. Eventually, they appreciated the opportunity to do so.

Grieving as Taken-for-Granted Actions

The adolescents' ways of coping with losses and the subsequent changes illustrated that they had taken for granted their ways of being in the world, their "habits" embodied in their social encounter (James, 1890/2004). For example, the darkness the participants experienced was a private issue seldom shared with others, and this way of dealing with the darkness was taken-for-granted knowledge in their situated cultures, specifically Korean society. Thus, initial tension between participants and the researcher was inevitable in uncovering the adolescents' experiences. The participants appeared uncomfortable with what they perceived as darkness-related questions, such as mentioning death or dying, talking about a friend's funeral in front of their parents, dealing with fears of cancer relapse or their own death as well as avoiding burdening others in order not to make others feel uncomfortable. Because the adolescents had kept their darkness to themselves, their grief and grieving were barely recognized by others, and more importantly, not even by themselves.

Cooley (1902/2004), in his elaboration of the concept of "looking-glass self," stated “Each to each a looking-glass reflects the other that doth pass (p. 185).” Korean adolescents with cancer saw and found themselves by looking at other cancer peers or their family members and could counter-see themselves within the mirror-like interactive structure. This feature of the social self which is highly valued in Confucian society may have influenced or reinforced the adolescents’ pattern of keeping the darkness. Grieving alone, hiding emotions, or feeling distressed due to prolonged periods of expressing emotion might have reflected what they socially acquired by observing how others grieve within Korean society.

Grieving in Relational Contexts

Participants grieved in relation to others, either friends or their family members. For example, Korean adolescents with cancer valued burden-bearing themselves so as not to further hurt their mothers (Chapter 3). The adolescents talked about their experiences more openly when they knew how other participants responded to the researcher’s questions (Chapter 4). These features illustrate how developmental tasks such as identity/confusion or intimacy/isolation in adolescence might interfere with the grieving of Korean adolescents with cancer. Studying the relationships among adolescents and their mothers, and other family members, is indicated as an avenue for further learning. In particular, exploring mothers as protectors or restraints based on the attachment formed through long-term care for children with cancer, emotion regulation and lack of privacy from the perspectives of the adolescents, and burden-bearing, are areas requiring further attention.

Employing a developmental contextual perspective (Lerner & Spanier, 1980) might provide an integrated framework that embraces these relational components for further study (Lerner, 1984, 1990, 1998). That is, the findings suggest there would be merit in studying (a) the action of individual adolescents on contexts, (b) the action of contexts on individual adolescents, and (c) the relation or co-action between the individual and the contexts (Gottlieb, 1991, 1997). These become especially important within various cultural contexts.

Implications for Nursing

Implications for Practice

People that we, nurses, care for vary in their ways of expressing grief. Like my participants, some individuals, particularly Asians, are reticent in expressing their grief while some others, notably many Westerners, are more likely to be open about sharing their experiences, including experiences with grief. The findings of this study indicate that Korean adolescents had a difficult time when they tried to deal with their grief by themselves without sharing with or seeking support from others. Thus, as nurses, we must learn optimal ways of providing support to such adolescents. We must realize that their lack of affective disclosure can mislead us to conclude that their grief is temporary or that they do not need our help (Martin & Doka, 2000). Instead, nurses working with grieving adolescents, Korean or other Asians in particular, need to appreciate the grievers' social relationships, both horizontal (i.e. equal-equal, adolescent-adolescent) and vertical (i.e. senior-junior, parent-child), that are based within the Confucian value of hierarchical order (Kim, 1995). It is natural that Asian grievers more willingly, although still reluctantly, better share their grief with others in an equal position. Thus, when Asian children or adolescents grieve, parents or other authority figures such as nurses, might not be good for grief communication unless the children or adolescents consider the adults as their trusty friends. To effectively communicate with and support them, nurses must attempt multiple strategies, such as were employed in this study. In addition, self-help groups among young grievers of similar cultural backgrounds or anonymous counseling by trusted adults can be other strategies.

Implications for Research

This dissertation is the first study that directly explored grieving in adolescents with cancer. The description of encountering darkness and its spiral feature focuses on Korean adolescents with cancer. Prospective studies with adolescents from other cultures and with other chronic diseases are needed for building a theory of illness-related grieving. In addition, examinations of how these adolescents grieve as they transition into adulthood would contribute to the development of such a theory. Future research using an ethnographic approach could be used to further knowledge development as well. For example, micro-ethnography may focus on a group of hospitalized adolescents with cancer or on a group of Asian mothers who have a child with cancer.

Limitations and Strengths of the Study

Limitations

Limitations in this study must be addressed. The sample included only participants from one university-affiliated hospital. Participants were mostly male adolescents (12 of 15 in total), and who were involved in regular social events that the hospital provided to the patients registered at the hospital. Thus, adolescent cancer survivors living in rural areas or those who were treated in local hospitals with lesser opportunities of being connected with other fellow patients, and female cancer survivors, were underrepresented. Retrospective data collection also has shortcomings in terms of events or memories that can be recalled exactly. However, qualitative research focuses on what is meaningful to the participants, whether or not their recall of events is “accurate” in some objective sense. At the same time, cross-sectional or prospective data collection regarding a certain loss-related event might be helpful in obtaining more detailed descriptions of the experiences of adolescent cancer survivors.

Strengths

Grief among survivors of childhood cancer is a new area of study about which knowledge is lacking. Thus, a major strength of this study is that it is the first study to describe how adolescent cancer survivors grieve facing the death of someone who was ill with the same disease, and the impact this has on their lives. Grounded theory methodologies allowed for rich descriptions of adolescents’ grief experiences, of their experiences with darkness. Use of various approaches to gather data was also a strength in that they facilitated optimal data collection. This study also examined the concept of filial piety to the grieving adolescents with cancer with regard to their relationships with their mother. Findings made clear how the complexities of human relationships, emotional responses, and cultural considerations influenced the process of grieving among the adolescents. This enhanced understanding emphasizes the potential need for grief and bereavement support for populations of various cultural backgrounds, as well as for the need for extended support of cancer survivors outside of the hospital setting.

Lastly, I cite van Manen’s accounts of ‘care as worry’ reflecting my experience of conducting this dissertation study. My journey was one way of caring as a nurse, a responsibility coming from my worry that adolescent cancer survivors might have a hard time in grieving alone. My relationships with them throughout the study were at times difficult, especially in the beginning, but ultimately, I came to see these challenges as a valuable learning opportunity. I learned that I could do good for the participants who were experiencing such darkness by helping them open their thoughts and feelings, and as result, feel less alone.

> Only by remaining sensitive to our unique responsibility can we insert into our professional ethical practices the lifeblood of caring, in all its various modalities, that our vocations require. For the pragmatically minded, this may be a bit of a heavy idea. Caring as worrying is no doubt a burden of responsibility. It may not always be pleasant or delightful, but as Levina says (cited in Rotzer, 1995, p. 61), it is good: It’s the experience of the good, the meaning of the good, of goodness. Only goodness is good (van Manen, 2002, p. 277).

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Appendix I

What is it like when you lose friends to cancer?

We are exploring adolescents’ thoughts and feelings following the deaths of friends to cancer. If you were diagnosed with cancer and had to say “good bye” to one of your friends with cancer who died, please share your story with us to help improve health care for childhood cancer survivors.

This study is confidential!

If you decide to participate in the study, this will happen:

1. The researcher (a nurse whose name is Ms. Jin) will talk to you on two occasions to hear your thoughts about what happened to you. The interviews will be private and will be done at a time and a place that is convenient for you.
2. If you allow her to, Ms. Jin will attend and watch what happens while you are in self-help group activities. She will also ask you if she can read your Web diaries that are open to the public.

If you have any questions regarding your participation in this study, contact Ms. Juhye Jin today at (010)-[redacted] or [redacted]@gmail.com. You can also give this sheet back to your doctor (Dr. Lyu) after filling out your contact information below. If you decide to participate or not, it will not affect your care at the [redacted] Medical Center. It’s up to you. This is completely voluntary.

☐ **Ms. Jin can call me: My name is ______________________**
Numbers to call me is ______________ or __________________

☐ I will contact her

☐ No thanks

Appendix II

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Bereavement Experiences of Korean Adolescent Survivors of Childhood Cancer Who Have Lost Friends to Cancer

This is a research study about understanding how adolescents who have survived cancer respond to the loss of a friend to cancer. The study researchers, Juhye Jin, RN, a doctoral candidate and Betty Davies, RN, PhD, Professor from the UCSF Department of Family Health Care Nursing will explain this study to your child.

Research studies include only people who choose to take part. Please take your time to make your decision about your child's participation in this study. If you have any questions, you may ask the researchers.

You child is being asked to take part in this study because your child was diagnosed with cancer and has experienced the death of his or her friends from cancer.

Why is this study being done?

The purpose of this study is to explore grief and bereavement in Korean adolescent survivors of childhood cancer following the deaths of friends to cancer.

This study is a private dissertation project. Juhye Jin, a PhD candidate, pays for the costs of conducting her study.

How many people will take part in this study?

About 15-25 people will take part in this study. The population will be Korean adolescent survivors of childhood cancer who are between the ages of 13 and 23 and are registered at a university affiliated hospital ([redacted]) in Korea.

What will happen if my child takes part in this research study?

If your child agrees, the following procedures will occur:

1. Ms. Jin will interview your child about his/her thoughts and feelings about the deaths of his/her friends from cancer. An audiotape will be made of the interview.
2. The personal interview with Ms. Jin will be conducted privately, in a location where your child feels comfortable. Ms. Jin will interview your child either once or twice, with each interview lasting no longer than 90 minutes.
3. If your child permits, Ms. Jin will conduct and record observations while your child participates in self-help group activities, and may review your child's Web materials that are open to the public. Please see the box(es) below for the activities in which your child agrees to participate.
   - ☐ Face-to-face interview ☐ Phone interview ☐ Internet chat
   - ☐ Being observed ☐ Sharing Web journals with Ms. Jin

How long will my child be in the study?
Participation in the study will take a total of about 60-180 minutes over the course of 6 months, depending on how many times your child is interviewed.

The total hours of participant observations depends upon how many times the researcher will be allowed to attend participant self-help group meetings. The length of the meetings varies from 1 hour to 3 hours. The researcher, Ms. Jin, expects to have at least three opportunities to observe, resulting in a total of 3-9 observation hours.

Can my child stop being in the study?
Yes. You child can decide to stop at any time. Just tell the researcher right away if your child wishes to stop being in the study.

What side effects or risks can my child expect from being in the study?

- Some of the questions asked by the researcher are likely to produce unpleasant feelings. If your child does not wish to answer or to stop the interview, your child will be able to decline to answer any questions at any time regardless of the planned time.
- The researcher may make your child feel uncomfortable. Your child can choose not to allow her to observe him/her, or to stop the observation any time he/she wants, regardless of permissions made by you or of his/her previous consent.
- For more information about risks and side effects, ask the researcher.

Are there benefits to taking part in the study?
There will be no direct benefit to your child from participating in this study. However, the information that your child provides may help health professionals better understand/learn more about how adolescents think about and cope with friends' deaths from cancer, a disease which also afflicts them.

What other choices does my child have if my child does not take part in this study?
Your child is free to choose not to participate in the study. If your child decides not to take part in this study, there will be no penalty to him/her. Your child will not lose any of his/her regular benefits, and your child can still get his/her care from our institution the way he/she usually does.

Will information about my child be kept private?
We will do our best to make sure that the personal information gathered for this study is kept confidential. However, we cannot guarantee total privacy. Your child's personal information may be given out if required by law. If information from this study is published or presented at scientific meetings, your child's name and other personal information will not be used. Organizations that may look at and/or copy the research records for research, quality assurance, and data analysis include:

- UCSF's Committee on Human Research
- [redacted] Hospital) Institutional Review Board
- UCSF School of Nursing Faculty (Ms. Jin's dissertation committee members)

Participation in this study may involve a loss of privacy. However, study records will be kept as confidential as is possible under the law. No individual identities will be used in any reports or publications resulting from this study. Study records and audiotapes will be kept in locked files at all times during the study, and only study personnel will have access to the data. After completing this study, the audiotapes will be destroyed thoroughly. The transcripts, however, will be kept in a locked file by the investigators.

What are the costs of taking part in this study?
Your child will not be charged for any of the study treatments or procedures.

Will my child be paid for taking part in this study?
Your child will receive a 10,000 won bookstore gift certificate after the first interview.

What are my child's rights if my child takes part in this study?
Taking part in this study is your child's choice. Your child may choose either to take part or not to take part in the study. If your child decides to take part in this study, he/she may leave the study at any time. No matter what decision your child makes, there will be no penalty to him/her in any way. Your child will not lose any of his/her regular benefits, and he/she can still get his/her care from our institution the way he/she usually does.

Who can answer my child's questions about the study?
Your child can talk to the researcher(s) about any questions or concerns about this study. **If your child has any questions, comments, or concerns about taking part in this study**, your child can first talk to the researcher, Juhye Jin, at 1-4[redacted] (or at 010-[redacted]in Korea)[redacted]@ucsf.edu. If for any reason your child does not wish to do this, or your child still has concerns after doing so, your child may contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

Your child can reach the CHR office at **415**[redacted], 8 am to 5 pm, Monday through Friday. Or your child may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

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CONSENT

I have been given a copy of this consent form to keep for my own records.

PARTICIPATION IN RESEARCH IS VOLUNTARY. My child has the right to decline to participate in this study, or to withdraw from it at any point without penalty or loss. My child can refuse to participate in this study even if I, as their parent, give permission.

______________ ____
Date Signature of Parent

______________ ____
Date Person Obtaining Consent

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
ASSENT TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Bereavement Experiences of Korean Adolescent Survivors of Childhood Cancer Who Have Lost Friends to Cancer

A. Why are we meeting with you?

We are doing a study about understanding how adolescents who have survived cancer respond to the loss of a friend to cancer. We are asking you to help because you have experienced the death of at least one friend from cancer.

B. What will happen to you if you are in this study?

1. A nurse whose name is Ms. Jin will ask you some questions about how you've dealt with the death of friends from cancer. Please talk freely with her about your thoughts and feelings. The interview will be audio-taped.

2. Ms. Jin will interview you at a time and place where you feel most comfortable. Your parent(s) will not be there. You will be interviewed once or twice if it is OK with you and each interview will last no longer than 90 minutes.

3. Ms. Jin will join you when you are getting along with your friends with cancer in self-help group meetings. She will record what you and your friends are doing during the meetings. She will also review your Web diaries if you have them.

Please check box(es) below for the activities in which you agree to participate.
☐ Face-to-face interview ☐ Phone interview ☐ Internet chat
☐ Being observed ☐ Sharing Web journals with Ms. Jin

C. Will any parts of the study hurt?

Talking about your experiences of a friend's death may bring up unpleasant feelings. At any point during the interview, if you don't want to continue, you can skip to a different question or end the conversation completely.

D. Will you get better if you are in this study?

You may feel better by expressing your inner feelings and thoughts. We hope that this will happen.

E. What if you have questions?

You can ask questions any time you like. You can also talk to me or you can talk to someone else.

F. What are your choices?

Signing this paper means that you have read this paper or had it read to you and that you want to participate in this study. If you don't want to be in the study, don't sign the paper. Remember, being in the study is entirely up to you. No one will get mad if you decide not to sign this paper, or if you change your mind later. Even if your parent(s) gave permission for you to participate, you have the option not to sign.

I _________________ (your name) have been told about this study. I have been told what will happen to me and how this might affect me. I have been encouraged to ask questions and have had my questions answered. I agree to participate in this study, and I sign below.

_____________ ____
Date Signature (You may mark √, if you are not able to sign your name)

_____________ ____
Date Signature of Person Obtaining Assent

Appendix III

INTERVIEW GUIDE

For the purpose of this study, semi-structured interviews are planned as a means of obtaining adolescent participants' bereavement experiences after the deaths of their cancer peers. The questions below are examples of those that the Co-PI will use to initiate a conversation with the participants. During the course of the interview other questions and probes may be used to clarify and expand the content being presented by the participants. The interviews will be conducted in Korean and in a location agreed upon by the interviewee. Prior to the beginning of the interview, Ms. Jin (Co-PI) will communicate with the participants to remind them of the interview dates and times.

Introduction

Thank you so much for agreeing to talk with me. I would like to review with you the purpose of this study. I am interested in exploring what it is like when you lose your friends to cancer. I want to remind you that everything you say is important and confidential. If you are uncomfortable or feeling tired, you can stop the interview, decline to answer a question, or take a break anytime during the interview today. I will be tape-recording and/or writing notes our talk today. Is that okay?

Interview Questions
(Only the Interview question and probes will be asked of participants)

Aim 1: To explore how loss of friends experienced by adolescent cancer survivors impacts changes in survivors' relationships with others, both family and friends.

Research Question 1: How has the loss of a friend affected your other relationships with family, friends, and new potential friends?

Interview questions and probes:

I would like to know about any situation where a friend died. Tell me any story about losing your friend from cancer

Probes: (Probing questions will be used as needed to stimulate further description.)

a) Could you tell me about your last farewell with your friend with cancer?
b) How did you know and find out about your friend who was dying or had died?
    - Do you remember the first time you heard of your friend's death?
    - What were you told?
c) What were your reactions then?
d) How have your friends' deaths influenced you?
e) What did you feel or think about the death of your friend at that time?
f) Was there anyone out there whom you could share your feelings and thoughts with?
    - If there is one, who was the person, and in what ways was it helpful to you?
    - If no one was available, how did you deal with your grief?

g) Was there any talk with family or friends about death and dying from cancer before it actually happened?

Let's talk about your family. Please tell me what your family has been like since you became ill with cancer.

Probes:

a) Who have been you closest to in the family?
b) How would you describe that person(s)?
c) What would you do together that was special since you were ill?
d) Do you recall any stories about the relationship with the person?

3) Tell me about your friends since before you were diagnosed with cancer.

Probes:

a) Who were your friends and who are your friends now?
b) If you have a special/close/best friend, how would you describe him/her?
c) What did/do you usually do with your friends? (those with and without cancer)
d) What's different about your friendships with other kids with cancer and other kids who don't have cancer?
e) Tell me about good or bad memories you have of your friends.
f) Is there anything that you regretted not doing in relation to friends?

Aim 2: To examine what relationship factors help or hinder the adolescents' bereavement experiences.

Research Question 2: What are the factors associated with adolescent cancer survivors' relationships with family or friends that help or hinder their bereavement experiences?

Interview questions and probes

1) Let's think about a specific situation when you lost a friend.

Probes:

a) What helped you most during your grieving?
b) What made it harder for you to deal with your grief?
c) Is there anyone who has been helpful or unhelpful to you in grieving?
    - If you could talk to any person about your thoughts and feelings, who would it be?
    - What would you talk about?

Aim 3: To identify societal or cultural impacts on their grief and bereavement.

Research Question 3: How does Korean culture and society influence grief and bereavement in adolescent survivors of childhood cancer?

Interview questions and probes

1) Do you think that your grief over the death of a friend might be different if you belonged to another culture?
2) How do you think Koreans think about cancer in children/adolescents?

3) How do you think Koreans think about death and dying from cancer?
4) How do you think your parents think about death(s) from cancer?
5) Have your thoughts on grief and bereavement changed since you have lost your friends to cancer?

   Probes:
   a) Can you describe what it was like before and what it is like now?
   b) Can you provide concrete examples or a story related to this?
   c) How has the change affected you?

Closing:

1) Is there anything else you'd like to tell me?
2) Is there anything else that I should know about?
3) How would you think about our talk today?
4) How do you feel having shared your story?

Thank you so much for sharing your story with me.

Appendix IV

Demographic Questionnaire

Date of Record: ______________________________

Participant ID (#): ____________________________

Location of Interview: _________________________

Age: _______________________________________

- Diagnosed with Cancer at Age: ____________________________________
- __________________________ Year(s) of Continuous Complete Remission

Gender: _____________________________________

Type of Cancer Diagnosis: _____________________________

Total Length of Hospital Stay for Cancer Treatments: ______________________ year(s)

Cell Phone #: _________________________________

Home Phone #: ________________________________

Email Address: ____

Personal Internet Homepage Address (if available):

____

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Author Signature

08/25/09

Date