

Communication Challenges in Korean Families Coping With Adolescent Cancer

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PURPOSE: To examine the family communication experience of Korean adolescents with cancer and their parents, including how adolescents and their parents verbally share feelings and concerns related to the adolescent's cancer diagnosis with one another, and how emotional communication affects parent-adolescent relationships and the family's coping abilities.

PARTICIPANTS & SETTING: 20 participants (10 adolescents with cancer, aged 13–19 years, and their parents) at a university-affiliated hospital in Seoul, South Korea.

METHODOLOGIC APPROACH: Individual, semi-structured interviews were conducted and analyzed based on a qualitative descriptive approach. Conventional content analysis was employed to analyze the data.

FINDINGS: The overarching core theme developed from the content analysis and theme generation was "I cannot share my feelings." This core theme is represented by three main themes: (a) restricted topics that I can share; (b) being closer, but a lack of depth; and (c) effects of restricted topics on their coping.

IMPLICATIONS FOR NURSING: Increased need for nursing awareness and culturally relevant assessment of emotional family communication needs between Korean adolescents with cancer and their family caregivers are necessary.

KEYWORDS Korean; family communication; adolescents with cancer; coping skills
ONF, 47(6), E190–E198.
DOI 10.1188/20.ONF.E190-E198

One of the biggest challenges that Korean adolescents with cancer and their families face is engaging in family communication. The resilience in illness model (RIM) defines family communication as the ability to share thoughts and feelings openly and clearly in stressful situations (Haase et al., 2014). Family communication plays a critical role in the positive adjustment of adolescents with cancer by developing resilience and self-transcendence (Haase et al., 2017), and works as a critical predictor of adolescents' satisfaction within their family (Akhlaq et al., 2013). Specifically, the ability to share emotional needs has been reported as essential for developing healthy coping strategies in children and adolescents (Ackard et al., 2006; Acuña & Kataoka, 2017; Gentzler et al., 2005) and in relieving physical and psychological distress after receiving a cancer diagnosis (Zebrack et al., 2010).

Despite its pivotal role, little attention has been paid to parent-adolescent communication in the context of Korean childhood cancer. Researchers have studied Asian cultural patterns related to protecting an ill family member from knowledge of their life-limiting condition (Kim et al., 2014). However, most studies of family communication have been conducted in Western countries. Existing studies have examined the effect of family communication on the relationships between Korean parents and healthy adolescents (Kim, 2018; Kim & Lee, 2019; Lee et al., 2018). Therefore, the purpose of this qualitative descriptive study was to examine the extent to which Korean adolescents with cancer and their parents verbally share feelings and concerns with one another, and how emotional communication affects parent-adolescent relationships and their coping.

Adolescents with cancer experience the highest level of distress (i.e., anxiety and depression) (Dyson et al., 2012; Jörngården et al., 2007). Specifically, Korean adolescents reported higher prevalence of

psychological distress than their counterparts in the United States (Kim & Yi, 2013). The diagnoses of cancer in adolescents also affects their parents. However, parents are one of the most important sources of support for adolescents with cancer across the illness trajectory (Cho et al., 2015; Harris et al., 2009; Kim & Yi, 2013; Long & Marsland, 2011; Rodriguez et al., 2013).

Despite modernized Korean culture by Western influences, traditional Korean belief in the family structure and relationships remains stable. Traditionally, Korean beliefs emphasize “we” rather than “I” in relationships. This is apparent in the family and often termed familism, wherein the family needs are more important than the individual needs (Kim et al., 2005; Kim & Rye, 2005). Korean familism prioritizes family by emphasizing strong bonding and cohesiveness rather than an individual’s rights. This Korean familism can present unique challenges to communication and can encourage individuals diagnosed with cancer to accept personal blame for their illness and the hardship that their treatment causes on the family (Kim & Kwon, 2013). Faced with these cultural norms, adolescents with cancer may feel discouraged or prohibited from discussing negative emotions. Ineffective intergenerational communication can result in a lack of information, misguided ideas about diagnosis or treatment, a sense of isolation (Jankovic et al., 2008), or the loss of beneficial palliative and therapeutic supports (Seth, 2010). Consequently, they can be at risk for maladjustment to the diagnosis of cancer (Murphy et al., 2016; Van Schoors et al., 2017) related to a perceived inability to meet role expectations, to verbalize feelings, or to express emotional needs.

Methods

The authors used a qualitative, descriptive design to explore Korean adolescents’ and their parents’ experiences related to therapeutic and emotional communication in the childhood cancer context (Sandelowski, 2000).

Setting and Participants

Convenience sampling was used to recruit Korean adolescents and their parents at a university-affiliated hospital in Seoul, South Korea. Adolescents were aged 13–19 years, had received a diagnosis of active cancer or were in remission, and communicated in Korean. Parents were self-identified as biological parents, step-parents, or legal guardians older than age 20 years who served as the primary caregiver. Potential study participants were identified by a physician in a research team and approached by the principal

investigator (PI) when they showed an interest in participating in this study. A total of 20 interviews were conducted across the sample (10 adolescents and 10 parents). Following 16 interviews, the authors reached thematic saturation when no additional themes were found (Francis et al., 2010). The remaining four interviews were conducted to search for any new information.

Data Collection

This study was approved by the institutional review boards of the Korean study site (for data collection) and North American site (for data transfer and analysis). Prior to each interview, the first author (study PI) obtained parental consent and written permission (for minor adolescent), and child assent for adolescents younger than age 18 years, or written consent from adolescent participants aged 18 years or older.

The PI developed a semistructured interview guide, based on the literature, and used the guide to collect data through in-depth, face-to-face interviews (see Figure 1). Participants were interviewed separately to maintain confidentiality. The PI conducted interviews in Korean, the native language of the participant. The PI audio recorded each interview and took field notes. Interview duration was approximately 30–40 minutes. With a single exception, interviews took place in a private room in the pediatric hematology oncology clinic; one interview was conducted at a participant’s home for convenience. When medical consultation was necessary because of sharing sensitive topics, a physician in a research team was available for ongoing assessment and necessary interventions.

FIGURE 1. Guide for Semistructured Interview With Korean Adolescents and Their Parents

- Please tell me about your communication with your parents/adolescents.
- What is good/positive/honest communication with your parents/adolescents, in your opinion?
- Please tell me about your engaging in good/positive/honest communication with your parents/adolescents.
- Please tell me about sharing your feelings and emotions with your parents/adolescents.
- Please tell me about your relationship with your parents/adolescents before the adolescent received a diagnosis of cancer.
- Please tell me about your relationship with your parents/adolescents after the adolescent received a diagnosis of cancer.

Data Analysis

The interviews were transcribed and the PI compared all transcripts to the original audiotapes. Early-phase translation and back translation (from English back to Korean) were conducted by independent professional translators to support careful and meticulous transcription of translated data (Lopez et al., 2008; Santos et al., 2014). Finally, two Korean-speaking researchers compared both versions of the transcripts to identify any mistranslations or inaccurate expressions in English.

Content analysis was used, in which two researchers read the interview transcripts independently several times to be immersed in the data and to begin development and refinement of the code book (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The two researchers then recoded the transcripts independently based on the code book. Discrepancies in codes were discussed throughout the analysis process to establish a consensus regarding recurring themes. The four different criteria of rigor, including credibility, transferability, dependability,

and confirmability, were met for this study (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Conducting the interview in participants' native languages, coding separately by two researchers, and collecting data from adolescents with cancer and their parents also enhanced trustworthiness of this study findings.

Findings

Table 1 presents the demographic information of the participants. The authors developed the overarching core theme of "I cannot share my feelings" as a synthesis of three main themes. The three main themes were (a) restricted topics that I can share; (b) being closer, but a lack of depth; and (c) effects of restricted topics on their coping. Each theme has several sub-themes that add to the richness of their description.

Restricted Topics That I Can Share

Acceptable topics for sharing: Although adolescents and parents felt they could not share emotionally charged feelings, there were some topics that were less emotionally charged that they felt they could share. Parents reported that, after their adolescent was informed of a diagnosis of cancer, both felt able to converse easily about daily activities such as appointments and treatments; they often discussed treatment plans, safety measures related to their compromised immune condition, medications, and dietary restrictions. A mother of a 14-year-old female diagnosed with a brain tumor described how she communicated about their daily life and health-related issues without difficulties.

As hospital visits become routine . . . when we go somewhere, I would tell her that you will need such and such shots, this drops your immunity level, so don't eat, and you have such and such number of treatments left, so hang in there, that sort of thing. When the treatment is over, you'll go through rehab, after that, you can walk, you'll go to school . . . those are the type of plans I share with her.

Unacceptable topics for sharing: Most adolescents and parents experienced difficulty in expressing and sharing their feelings and emotions with each other. A few adolescents reported that talking about physical hardship is easier than talking about psychological hardship. A number of parents also reported difficulty in sharing their concerns about the cancer diagnosis and prognosis with their adolescent. A 19-year-old male diagnosed with a rhabdomyosarcoma described

TABLE 1. Sample Characteristics (N = 20)

Characteristic	n
Parent economic status (n = 10)^a	
High	-
Medium	8
Low	2
Parent education (n = 10)	
High school graduate	7
College graduate	3
Adolescent diagnosis (n = 10)	
Brain tumor	4
Leukemia	2
Adrenal tumor	1
Rhabdomyosarcoma	1
Sarcoma	1
Unknown diagnosis	1
Adolescent time since diagnosis (n = 10)	
Within 3 months	2
3 months to 1 year	2
2-3 years	5
More than 3 years	1

^aHigh economic status is \$5,758 or greater per month, medium is \$2,578-\$5,757, and low is \$2,577 or less.

how he tried to hide negative feelings and to appear energetic and positive to his parents.

I cannot hide that I can eat nothing because of severe nausea or being exhausted, but I usually try to avoid expressing that I want to cry because of being exhausted or I am so afraid of receiving treatments. I usually tell them I am fine. It is alright, possible, to feel nauseous. I try to smile and be positive.

The most frequently reported barrier to engaging in family communication was a need to protect, the unwillingness of adolescents with cancer and their parents to share their concerns or emotions related to their worry that sharing would cause emotional harm. Both adolescents and parents were afraid of making each other worry by sharing their hardships. An 18-year-old female with an unknown cancer diagnosis described this feeling.

She was so sorry because I had all the pain and there wasn't a single thing that she could do to reduce that except handing over a painkiller, so she kept saying she was sorry; seeing how she is so sorry, I couldn't talk about my pain anymore. We haven't really had a deep talk about the disease . . . haven't gone into the details.

The mother of the this adolescent described how she hid her feelings, leading to frustration.

I had to smile when I see my daughter. I was just on the phone a while ago crying, and I had to explain why when I saw my daughter. My mom passed away in May, so I could use her as an excuse to explain myself crying. She's always sorry about everything, even when she's dying of pain. She apologizes for calling or waking me; sometimes that frustrates me.

In addition, their will to protect was related to the perception of a negative prognosis. One mother of an 18-year-old male diagnosed with embryoma explained that she was able to communicate with her son because his prognosis was positive. "I told him that if this was incurable and hopeless then it would've been difficult for me to tell him." Some parents felt that not understanding the prognosis made them afraid that they might lose their child. Several admitted that they avoided sharing negative feelings out of a belief that verbalizing them would cause their child to die. One

mother of a 15-year-old male diagnosed with an acute myeloid leukemia (AML) admitted that her concern about losing him prevented clear communication with her son.

My biggest concern, what I fear the most is losing him . . . it's OK if it's 100% curable or if we hear he can survive after all treatments, but you never know . . . so, I couldn't tell him at first. I was so scared.

Lack of prior experiences in parent-adolescent communication was a challenge to communication, as a father of a female adolescent with an adrenal tumor described.

I haven't communicated with her about her cancer. It's hard to bring up the issue. I try, but, as a father, suddenly approaching her would be a bit awkward. . . . She might reject me if I change my attitude all of a sudden. I think it's better to change slowly than abruptly.

Being Closer, But a Lack of Depth

Fostering a sense of "becoming a companion": As participants necessarily spent more time together after a cancer diagnosis, adolescents and parents reported developing a stronger bond and getting closer to each other. A 19-year-old female diagnosed with a brain tumor described this feeling: "Dad and I weren't close; we had this awkward distance, but I reached out to him after I got sick. He was someone I could count on."

Inability to share the depth of their emotions: This new feeling of closeness, however, did not necessarily allow them to share emotional needs. Parents admitted that they wanted to know what their adolescents were thinking, but refrained from asking. In fact, many parents said that their desire to learn about the adolescents' thoughts motivated their participation in this study. A mother of an 18-year-old male diagnosed with a brain tumor expressed her frustration from not knowing her son's thoughts.

Honestly, I don't really know what he thinks of his circumstances. He doesn't express things in detail. I just let him know he had a surgery for brain tumor that it's best to feel good and not to be stressed. The doctor comes in and says things worked out well and he would grin and say, "OK."

In addition, most parents and adolescents reported that there was a depth of feeling they could

not share, as described by a mother of an 18-year-old female with an unknown cancer diagnosis. “Yes . . . we like to talk to each other, but there’s this depth that you can’t share, as we talk more and more, I think, ‘This isn’t right. There isn’t any depth.’”

Bridging the gap by siblings: Sometimes, siblings played a pivotal role in bridging the communication gap between adolescents with cancer and their parents. Some adolescents and parents shared their hardships with adolescents’ siblings to gain help or advice instead of communicating with each other. A mother of an adolescent with an unknown cancer diagnosis stated: “We both try to, but I think she [the adolescent] avoids talking openly and deeply because I might worry. I hear about any concerns from my oldest daughter, her sister.”

Effects of Restricted Topics on Their Coping

Adolescents received comfort from having encouraging conversation with their parents. A 14-year-old female diagnosed with a brain tumor described how she was encouraged by her mother.

That my hair is growing back, and saying that I am getting better, encourages me a lot. Like, I’m doing well, that if I push a little more, I could overcome it all . . . those kinds of things.

One 15-year-old male diagnosed with AML admitted that he had never been comfortable expressing his feelings and had no encouragement to do so. He believed that this inability to express his emotions had caused his cancer.

I never really talk about my emotion or things like that. Never have. Every time I try to express it, it didn’t work well . . . maybe, that’s the reason I’m sick, because I never express much.

A 19-year-old female diagnosed with a brain tumor believed that she did not have a supportive relationship with her mother because of her mother’s unwillingness to communicate with her. This uncommunicative parent–adolescent relationship prevented the adolescent from sharing her psychological and emotional suffering. The adolescent admitted that she sometimes thought of committing suicide and regretted that she had been born. “I don’t think my mother listens to me. . . . Just sometimes, I want to die. If I wasn’t sick, I wouldn’t have made mom and dad have such a hard time.” The PI further assessed her for suicidal plans and found that she did not have

them. However, the protocol allowed for the PI to contact the pediatric oncologist, if needed.

When adolescents and their parents could not communicate well, they coped in isolation. A father of a 16-year-old male diagnosed with osteosarcoma admitted to self-medicating with alcohol to cope with stress rather than communicating his feelings to his son. He said that he did this to protect his son.

I need alcohol to speak out; therefore, I go to the convenience store and drink a bottle of soju [Korean alcohol] because I have no one to talk to about what I’m going through, specifically with my son. He is one of the most important persons in our family right now.

Discussion

The purpose of this study was to describe Korean adolescents’ and their parents’ family communication experiences, which have rarely been studied. The authors specifically focused on how Korean adolescents with cancer and their parents share their emotional needs and how their sharing affects their relationship and coping ability. Adolescents and their parents seemed to have an unspoken understanding that there were different types of communication, some of which were accepted for sharing between adolescents with cancer and their parents and some of which were not. Adolescents and their parents had no challenges communicating about the treatment or the day-to-day routines, and these discussions had a positive impact on their relationship and their personal coping. In some cases, parents’ encouragement of communication made adolescents feel relieved and helped them gain hope for the better outcome.

However, adolescents and parents often experienced challenges in communicating about emotions. These types of communication were termed, in this study, as unacceptable topics for sharing. Adolescents with cancer and their parents pretended they were feeling good while trying to hide their concerns from each other. This pattern of communication was defined as mutual pretending (Bluebond-Langner, 1980). This pattern of communication made adolescents and parents feel that they had a supportive but superficial relationship, and this resulted in unresolved negative feelings. The findings of the current study are consistent with those from other studies reporting the prevalence of adolescents feeling isolated and lonely (Jankovic et al., 2008; Kim & Kwon, 2013), and fear to ask questions about death or suffering (Seth, 2010) when

they fail to share their emotions. Parents also suffer when they cannot communicate with their adolescent (Kreicbergs et al., 2004). Parents who could not communicate openly with their adolescent suffered from feelings of lifelong regret and guilt after their adolescent's death.

According to social penetration theory, communication involving self-disclosure with depth and breadth is critical to advancing relationships between people (Altman & Taylor, 1973), particularly within families (Haase et al., 2017). This principle was apparent in the current study in that Korean participants who failed to share emotional needs also failed to advance their relationships, resulting in feeling of an inability to share the depth of their emotions.

In the interviews, participants discussed the diverse obstacles to communicating their emotional needs. The main obstacle was a desire to protect, closely related to a fear that sharing psychological suffering would inflict emotional harm. Therefore, a negative prognosis was related to greater fear. These findings were consistent with existing research findings from Western countries, despite cultural differences (Arruda-Colli et al., 2015; Bell et al., 2018; Clarke et al., 2008; Clemente, 2007; Kars et al., 2015; Nuss, 2014; van der Geest et al., 2015; Wangmo et al., 2017; Watanabe et al., 2014). This avoidance of communicating emotions to protect each other against being emotionally hurt was defined as a concept of double protection (Last, 1992). Korean adolescents and their parents paradoxically avoided family communication to protect each other; but their action caused negative results for all concerned.

The current study revealed that challenges to communication in Korean culture created serious risks for ineffective coping, including suicidal ideation, substance abuse, and magical thinking related to the cause of the illness. These risks necessitate increased nursing awareness and assessment. Prior research studies revealed that supportive parent-adolescent relationships characterized by higher-quality communication fosters psychological well-being and flourishing (Dunn et al., 2013; Grevenstein et al., 2019), and prevents internalizing symptoms (Ohannessian, 2012; Simpson et al., 2018; Xiao et al., 2011).

Limitations

Although this study includes a diverse sampling of participants with different diagnoses, small sample size and a lack of social diversity are limitations in this study. The authors conducted interviews at one

KNOWLEDGE TRANSLATION

- Engaging in family communication affects the parent-adolescent relationship and their coping.
 - Nurses should understand the effect of culture on family communication and assess suppressed emotional needs among Korean adolescents with cancer and their parents.
 - Development of a culturally appropriate assessment tool and interventions are needed to support Korean adolescents with cancer and their parents.
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point in time and did not explore the changes of Korean parent-adolescent communication across the illness trajectory. Therefore, future research should consider longitudinal study designs to gain further understanding of the family communication pattern across the illness trajectory and what factors affect the change or stability in those patterns.

Implication for Nursing and Research

The findings of this study have important implications for future practice and research. When assessing Korean adolescents with cancer and their parents, nurses should pay particular attention to their perceived inability to express emotions and any possible desire to suppress their emotions to protect family members. The importance of family assessment to support a family in the childhood cancer context has been reported in the literatures (Alderfer et al., 2008; Barakat & Alderfer, 2011). Employing direct observation of adolescent-parent communication can be an effective method to assess how adolescents with cancer and their parents communicate and the effect of communication on their coping or adjustment to a cancer diagnosis (Dunn et al., 2011).

When adolescents with cancer and their parents struggle to share their emotional needs because of their misconception related to family communication, nurses should provide them a chance to share their emotional needs. Throughout the interviews, adolescents with cancer and their parents emphasized the pivotal role healthcare providers play in encouraging adolescents with cancer and their parents to engage in therapeutic family communication. Parents appreciated receiving counseling when they first faced their adolescent's diagnosis and had no idea how to communicate with their adolescent. Participating in art therapy or support groups with peers also encouraged adolescents to share their concerns and emotions better with their parents. Nurses

can help families communicate the cancer diagnosis and any related emotions by helping parents identify their adolescent's symptoms and educating therapeutic communication skills between adolescents and parents to help their coping.

Although there is no currently existing family communication intervention, an intervention such as VitalTalk (2020), which is an intervention focusing on healthcare providers and patients, may be a good model to adapt. Nurses can also encourage therapeutic family communication by informing them of the desirable outcomes from engaging in family communication, such as fostering positive coping, resilience, and adjustment to the illness trajectory.

This study makes a unique contribution to the existing literature by exploring family communication experiences among Korean adolescents with cancer and their parents. This not only generates a new knowledge base about Korean families of adolescents with cancer, but also informs the necessity of culturally appropriate interventions for this population. Although there are guidelines emphasizing open and honest communication between adolescents with cancer and their parents in Western countries (Committee on Bioethics, 1995), it might not be culturally acceptable for Korean adolescents with cancer and their parents. Therefore, development of an instrument used to assess the family communication needs and vulnerable populations who are struggling to communicate should be prioritized. The generated knowledge from these efforts may inform the development of culturally appropriate interventions. Finally, this understanding will lead to a better understanding of Korean adolescents with cancer and their parents who have immigrated to Western countries.

Conclusion

This study provides important insights into the family communication experiences of Korean adolescents with cancer and their parents. Korean adolescent with cancer and their parents had no challenges in communicating about the treatment or day-to-day routines but experienced challenges in sharing emotions. These challenges in sharing emotional needs were related to their will to protect each other from emotional harm. This results in superficial relationships and discourages healthy coping. Nurses should be aware of any possible desire to suppress emotional needs in Korean adolescents with cancer and their parents and inform them of the positive outcomes from engaging in family communication, such as positive coping and adjustment to the illness trajectory.

Future research is necessary to develop culturally appropriate assessment tools and interventions for Korean adolescents with cancer and their parents.

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The authors gratefully acknowledge Jungwoo Han, MD, and the nurses in the hematology and oncology department at Severance Hospital in Seoul, South Korea, for helping with recruitment of study participants and data collection.

This work was supported by a Doctoral Degree Scholarship in Cancer Nursing from the American Cancer Society (131744-DSCN-18-071-01-SCN) to Son.

Son, Crego, and Docherty contributed to the conceptualization and design. Son and Docherty completed the data collection. Yang and Docherty provided the analysis and the statistical support. All authors contributed to the manuscript preparation.

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