



The influence of family management style on psychosocial problems of childhood cancer survivors in Korea



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A B S T R A C T

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Purpose: To examine the psychosocial problems of childhood cancer survivors in Korea and investigate whether such problems are influenced by family management style.

Methods: Family members of 158 childhood cancer survivors answered a questionnaire on demographic and illness characteristics, described psychosocial problems in their children using the Pediatric Symptom Checklist (PSC), and completed the Family Management Measure (FaMM).

Results: Perceived economic status and all six subscales of the FaMM were significantly correlated with children's psychosocial problems. In a multiple regression model, the Family Life Difficulty and Parental Mutuality scales of the FaMM were each independent predictors of psychosocial problems in young cancer survivors.

Conclusions: A detailed care plan designed to (1) promote balance between the management of a child's condition and normal family life and (2) encourage parents to share their feelings with one another and provide mutual support should be required to improve psychosocial outcomes for childhood cancer survivors.

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Introduction

Recent advances in treatment have increased survival rates for childhood cancer. For example, in Korea the 5-year survival rate for children under 14 years has increased from 55.8% in the 1990s to 72.1% in the 2000s (Ministry of Health, Welfare and Family, 2009). Over 80% of children diagnosed with cancer will become long-term survivors of the disease (Ahn, 2012; Howlander et al., 2011). Given the growing number of childhood cancer survivors, many health care professionals consider ongoing care to maintain the physical and psychosocial wellbeing of these patients as a vital responsibility.

Dealing with childhood cancer may influence physical and psychosocial health of children and quality of life of the family members (Stam et al., 2006; Zebrack et al., 2002). Physical challenges include compromised general health status, limited activity, interrupted developmental progress, and functional impairments. Adverse effects on psychosocial wellbeing are evidenced by low quality of life, high levels of psychological distress, including depression, somatic symptoms, problematic behavior, post-

traumatic stress, high suicide ideation, and low self-esteem, and impaired functional and social outcomes compared to healthy controls or siblings (Gurney et al., 2009; Kim et al., 2011; Langeveld et al., 2004; Maurice-Stam et al., 2008; Michel et al., 2010; Sim et al., 2010; Stam et al., 2006; Recklitis et al., 2009; Weiner et al., 2006; William Li et al., 2013; Zebrack et al., 2002; Zeltzer et al., 2008).

The psychosocial vulnerability of a child undergoing cancer treatment is mirrored by the effect of the disease on his or her family (Alderfer et al., 2009). Family members of a child suffering from cancer experience a variety of challenges themselves. A family's day-to-day activities may be altered, and future goals may be revised (Nelson et al., 2006). The greater the negative impact of a child's condition on his or her family's life, the greater the effect on the parents' psychosocial functioning; it has been shown that high levels of caregiver burden remain years after treatment has ended (Hardy et al., 2008). Signs of psychological distress, such as post-traumatic stress symptoms, loneliness, helplessness, and uncertainty, are reported more often in the parents of children with cancer than is the norm (Stam et al., 2006; Kazak et al., 2004).

Families often play a key role in caring for children who suffer from a chronic health condition. A family's cohesiveness and level of conflict may determine how well it can provide a young survivor with a better quality of life and compensate for a child's physical

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deficits (Hocking et al., 2011). Despite the recent change into westernized life style, the traditional culture of Confucianism still affect the family dynamic in Korean culture, which is often exemplified by strong ties between parents and a child, a parental devotion into their child, valuing family honor, and parents as an absolute authoritative being over their children. How the family members respond to a given situation, such as a child's cancer, may be correlated with how individual families with the ill child behave in their daily lives in a specific cultural background. Thus, understanding how family members perceive and manage family life with a vulnerable child may enable professionals to tailor interventions to a given family over the cancer trajectory (Deatrick et al., 2006).

The Family Management Style Framework (FMSF) is a conceptual representation of a family's response to a child's condition. The FMSF was developed after a thorough program of qualitative research and conceptual review (Knafl and Deatrick, 1990, 2003). It is designed to capture the interplay between how individual family members define key aspects of having a child with a chronic condition (Definition of the Situation), the behaviors they use to manage the condition (Management Behaviors), and their perceptions of the consequences of the condition for family life (Perceived Consequences).

The insight the FMSF provides into a family's strengths and challenges with regard to condition management (Knafl et al., 2012) has been used to guide health care for cancer survivors (Deatrick et al., 2006). For example, the FMSF describes strategies used by all or a subset of individual family members to manage and incorporate follow-up care into everyday life following completion of cancer treatment. Previous studies of families with children who have cancer or other serious illnesses have found that a normative view of the ill child and family life. This approach seeks to manage the illness-related demands of a child while sustaining life's normal patterns as much as possible (Deatrick et al., 2006).

A family's perception and management of a child's condition is believed to be a major factor affecting his or her psychosocial adjustment following cancer treatment. This may be a critical issue in a culture of strong parent-child bonds. However, few studies have investigated the effect of family management style on the psychosocial health of young childhood cancer survivors in a Korean culture. In this study, we examined the psychosocial problems of childhood cancer survivors in Korea and investigated whether such issues were influenced by family management style.

Methods

Sample and setting

In determining the inclusion criteria for our study, we considered both the criteria used in a previous study evaluating the psychometric properties of the original Family Management Measure (FaMM) (Knafl et al., 2011) and the age range appropriate for the Pediatric Symptom Checklist (PSC) (Jellinek et al., 1999). Our target sample included one accompanying adult family member with a child 4–16 years old who (1) was enrolled in the pediatric oncology department of Severance Hospital, a university hospital located in the metropolitan Seoul area, (2) had been diagnosed with a childhood cancer and had been seen for regular check-ups after completing cancer treatment that was assumed as 'remission', (3) had not been hospitalized within the past 2 months and whose parents were willing to participate. The specific medical diagnoses included leukemia, hepatoma, lipoma, osteosarcoma, and Wilm's tumor. Of the initial 167 participants recruited for the study, 160 family members completed the measurements due to time restraints. After excluding two questionnaires due to insufficient

responses, reports from the 158 adult family members of children were included in the analysis.

Data collection procedure

After obtaining approval from the Severance Hospital Institutional Review Board (4-2010-0579), data were collected with the cooperation of the hospital's pediatric oncology outpatient clinic staff, from November 2010 to February 2012. While children were waiting for their regular check-ups with physicians in the outpatient clinic, the accompanying family members, primarily the mothers, completed questionnaires. Written consent was obtained from the caregivers accompanying the children. The questionnaire took approximately 30 min to complete, and each participant received a token of appreciation after the questionnaire was completed. The child's official diagnosis and the duration of their illness were obtained from medical records.

Measurement tools

Demographic and illness-related characteristics

Gender, educational status, perceived economic status, and information on family structure were recorded for each accompanying caregiver, as well as the nature of their relationship with the child and the child's age. Information on the cancer diagnosis, the length of time the child had suffered from cancer, and the perceived severity of the child's condition as reported by the accompanying caregiver, using a 10-point visual analog scale (VAS), reported from 1 (no severe) to 10 (extremely severe), was also included.

Psychosocial problems of childhood cancer survivors

The Pediatric Symptom Checklist (PSC), which identifies children's emotional and behavioral problems based on their parents' impressions, is a widely used instrument in comprehensive pediatric care settings that yields consistent results across groups (Jellinek et al., 1999).

In this study, the Korean version of the PSC (Kim and Lee, 1989), adapted from the original PSC (Jellinek et al., 1988), was used to measure the psychosocial problems of childhood cancer survivors. This questionnaire is composed of 35 items asking about a parent's impressions of his or her child's emotional and behavioral problems. Some examples of items are 'has trouble concentrating,' 'is irritable, angry,' and 'does not show feelings.' Parents mark each item using a 3-point scale (options include never (0), sometimes (1), or frequent (2)), and the total sum is calculated. The PSC includes three subscales that identify specific mental health problems, one each for attention, internalizing, and externalizing, and the total score can range from 0 to 70. A higher score indicates that a parent perceives more psychosocial problems in a child. The scores that indicate psychosocial problems requiring attention from a medical or mental health professional are 28 and 24, respectively, for children 6–16 years or 4–5 years. The Cronbach's alpha coefficient for the PSC in this study was 0.89.

Family management style

To assess the family management style of childhood cancer survivors, we used the Korean version of the FaMM (Kim and Im, 2013), which was created via forward-backward translation of the work of Knafl et al. (2011). The original FaMM, developed based on the dimensions of the FMSF, was created to measure parents' perceptions of family management when caring for a child with a chronic illness/condition (Knafl and Deatrick, 2006; Knafl et al., 2008; Knafl et al., 2011).

Like the original FaMM, the Korean FaMM utilizes a five-point scale anchored by "strongly disagree" and "strongly agree" and is

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