



## The lived experiences of aboriginal adolescent survivors of childhood cancer during the recovering process in Taiwan: A descriptive qualitative research



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### ABSTRACT

**Purpose:** The purpose of this study was to understand the experiences of Taiwanese aboriginal adolescent survivors of childhood cancer during the process of recovery.

**Method:** A snowball sampling strategy was used to recruit participants from the pediatrics unit of a medical center in the eastern region of Taiwan. In-depth interviews were conducted with 11 aboriginal adolescent childhood cancer survivors. The data were analyzed using content analysis.

**Results:** The results revealed three major themes with subthemes within each theme. The three major themes are: roots of resilience, transformation and growth, and meaning of traditional rituals for resilience. The three subthemes within “roots of resilience” include: “feeling secure through company of family, care and financial support”, “receiving support from the important others and religion” and “learning to self-adjust”. The three subthemes revealed within “transformation and growth” are: restructuring the relationship with peers, “appreciating parents’ hard work”, and “learning to seize the moment”. The two subthemes within “meaning of traditional rituals to resilience” include: “feeling blessed with the power of ancestral spirits” and “strengthening ethnic identity”.

**Conclusion:** This study provided insight into the experiences of aboriginal adolescents as they recovered from childhood cancer. The experiences made positive impacts by inspiring growth in maturity and consolidating aboriginal ethnic identity. The adolescents were empowered by support from family, friends and clansmen, and by their participation in aboriginal rituals. As healthcare professionals care for the aboriginal adolescents, it is critical to consider this culturally and ethnically specific knowledge/experience of surviving cancer to improve quality of care.

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## 1. Introduction

Cancer is one of the leading causes of death among children and adolescents in Taiwan (Ministry of Health and Welfare, 2014).

According to the decennial survey by the Taiwanese Childhood Cancer Foundation (2010), the average 5-year survival rate in children with cancer increased from 55% in 1993 to 70% in 2004. Among Taiwanese aboriginal adolescents aged 15–24, the mortality rate of childhood cancer is 1.1 times higher than that of their non-aboriginal counterparts (Council of Indigenous Peoples, 2014). Statistics regarding the survival rate of childhood cancer among aboriginal children is lacking in the Taiwanese literature. In general, the current literature on children with cancer focuses on the effectiveness and side effects of cancer treatment, symptoms of distress and quality of life. Only a limited number of studies have

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addressed the recovery process from childhood cancer in aboriginal cancer survivors.

### 1.1. *Surviving cancer among adolescents*

Recovering from childhood cancers has both positive and negative impacts in adolescent cancer survivors. [Servitzoglou et al. \(2008\)](#) examined the psychosocial wellbeing of Greek adolescent and young adult cancer survivors. While emotional difficulties resulting from the past cancer experience were reported, the participants also demonstrated satisfactory long-term psychosocial wellbeing and development of a positive view toward their lives. Approximately 44.7% of the participants stated that they became more emotionally mature; learned to appreciate life; found more tenacity and abilities in themselves to handle difficulties; and were less bothered by trivial matters. [Hsu \(2009\)](#) explored the experiences of adolescent cancer survivors and their mothers. The results showed that the emotional and physical impacts of cancer on the adolescents and their mothers persisted even after completion of the cancer treatment. With support from families and society, they were able to regain strength and adapt. [Björk et al. \(2011\)](#) utilized the hermeneutical phenomenological approach to explore the experiences of pediatric cancer survivors and their families. The results showed that the families reestablished normalcy in life after completion of cancer treatment, and developed appreciation of closeness with others (especially with their family members). [Duran \(2013\)](#) found that the adolescent cancer survivors and their parents experienced post-traumatic growth such as discovering the meaning of life, learning to appreciate life, cherishing closeness with family, and developing a willingness to contribute to society. Cancer was viewed as one of their best teachers that nurtured the development of a deeper understanding of the self and the world.

### 1.2. *Cancer recovery process in aboriginal adolescent survivors*

Currently no study has focused on the cancer recovery process in Taiwanese aboriginal adolescent cancer survivors. However, studies have been conducted to investigate the process of recovering from major life traumas (such as natural disasters) among Taiwanese aboriginal adolescents. [Chen et al. \(2013\)](#) compared the Han and aboriginal ethnic groups in their adaptation and coping strategies after surviving the 2009 typhoon Morakot (Taiwan). The aboriginal participants tended to use the “self-becoming” coping strategies (making adjustments to the internal environment of self), whereas the Han participants used the “external-change” coping strategies (making adjustment to the external environment). [Hsieh \(2013\)](#) conducted a qualitative research to understand aboriginal adolescent survivors' experiences of coping with trauma from typhoon Aere in 2004 (Taiwan). The results indicated that the participants' post-disaster psychological trauma was alleviated by the comfort and prayers received from weekly gatherings with their clansmen. In addition, the aboriginal adolescents remained optimistic after the typhoon. Such a positive attitude was attributed to their natural sense of humor and tribal honor of a courageous and warrior-type character facing challenges ([Chen, 2005](#); [Chen and Shu, 2008](#)).

### 1.3. *Impact of culture*

Culture and ethnic background are the factors that impact adolescent resilience as they face challenges such as cancer ([Haase, 2004](#); [Wallace et al., 2007](#)). Nevertheless, very few studies in the Taiwanese literature focus on the impact of culture and ethnic background on the adolescent cancer experiences and the recovery processes. In Taiwan, the aboriginal population – which comprises

approximately 2.1% of the total population – involves 14 tribes with distinct cultures, languages, customs and social structures ([Council of Indigenous Peoples, 2014](#)). The aboriginal families are generally lower in socioeconomic status than the Han ethnic group (the majority group), and they reside in rural areas with poor medical resources (such as the Hualang and Taidon regions). They are distinctive in their optimistic personality trait, closeness/togetherness with family, and strong connections/interactions with the community; they greatly esteem their traditional tribal rituals (such as harvest festival and ancestral spirits festival). This ethnic distinctiveness has been perceived as cultural resilience ([Chen et al., 2013](#)). In the aboriginal communities, adults pass the traditional cultural concepts and beliefs on to children through participation in the community activities, and interactions with clansmen. Handover of the cultural heritage facilitates the development of resilience of the individuals and the community facing challenges ([Chen et al., 2013](#)). However, the specific impact of community and the aboriginal ethnic characteristics/background on the recovery processes of adolescent cancer survivors is unknown.

The researchers' observations reflect that aboriginal adolescent's humorous and optimistic personality traits and participation in the traditional aboriginal rituals seemed to encourage them to handle cancer with a positive attitude. Further investigation is necessary to verify the accuracy of such clinical observation, and to understand the impact of the aboriginal culture on their cancer recovery process. Therefore, the purpose of this study was to understand the lived experiences of Taiwanese aboriginal adolescent survivors of childhood cancer in the recovery process.

## 2. **Methods**

### 2.1. *Research design*

A descriptive qualitative research method was used to understand the lived experiences during recovery from cancer in Taiwanese aboriginal adolescent cancer survivors.

### 2.2. *Participants/setting*

A snowball sampling strategy was used to recruit a convenient sample of participants in a medical center in East Taiwan. The inclusion criteria included adolescents: (1) aged between 12 and 18 years old, (2) who had been diagnosed with cancer and had finished cancer treatment for over a year at least, (3) who were aboriginals, (4) who assented to the study (consent was also obtained from the parents/legal guardians), and (5) who were able to communicate in Mandarin.

### 2.3. *Data collection/data analysis*

One-on-one audio-recorded in-depth interviews were conducted from August to December 2012. A semi-structured interview guide was developed prior to data collection to be used for the interviews (see [Table 1](#)). Recruitment of participants continued until data saturation, i.e., occurrence of repetitive themes with no emergence of new data. All of the interviews were conducted by the same researcher.

### 2.4. *Procedure*

IRB approvals were obtained from the Council of Indigenous Peoples and Aboriginal Tribes and a medical institution review board. Prior to conducting the interviews, the researcher explained the purpose and procedure of the study to potential participants

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