



## Coping strategies of children treated for leukemia in China



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### ABSTRACT

**Purpose:** To describe the coping strategies and preferred coping style of Chinese children with leukemia during hospitalization.

**Methods:** In-depth interview with a semi-structured interview were conducted with 29 Chinese children who underwent leukemia treatment. The Krippendorff's content analysis method was used to data analysis.

**Results:** During the hospitalization, children had three ways of psychological adjustment: Self-regulation, assistance of health professionals, helping of parents. There were many coping strategies. Problem-focused coping included seeking information and problem solving, and emotion-focused coping included seek emotional support, self-control, acceptance, seeking other rewards.

**Conclusions:** Children use different coping styles consistent with their cognitive development stage, and Chinese traditional culture affects children's coping strategies.

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### 1. Introduction

Childhood leukemia is the most common pediatric malignancy, with 5-year survival rates of 84%–90% (Landier, 2011; Hunger et al., 2012). About 75% of pediatric leukemic cases are diagnosed as acute lymphocytic leukemia (ALL). The total length of therapy for most ALL treatment plans is 2–3 years, including a 1-month induction treatment period to achieve remission, an intensive 1- to 2-month consolidation treatment program, and about 2 years' maintenance chemotherapy (Psychiatry, 2009; Han et al., 2010; Landier, 2011). In China, pediatric leukemia patients require two to three months of in-patient treatment to achieve initial remission and consolidate the disease. Additionally, patients will be hospitalized for two-week interludes during every course of the two-to three-year maintenance chemotherapy period; intermittent chemotherapy courses are separated by at-home rest periods (Han et al., 2010). Chemotherapy in children with leukemia is usually intensive, consisting of a lengthy, invasive and arduous treatment flow (Kars et al., 2008), as well as a variety of treatment side-effects. The medical experiences occurring during leukemia treatment such as lumbar punctures, blood tests, chemotherapy side-effects, long-term hospitalization, and restrictive infection prevention regimens

can be the sources of psychological stress in children (Kars et al., 2008).

Research findings about pediatric adjustments to cancer are inconsistent. Some studies showed that survivors coped well with the extreme stress of the disease and treatment (Polizzi et al., 2015); behavioral problems were significantly less frequent in survivors than their healthy peers (Nazari et al., 2014). In contrast, other studies indicated an increased risk of developing emotional problems, low self-esteem, and symptoms of post-traumatic stress (Psychiatry, 2009; Myers et al., 2014).

Coping involves cognitive and/or behavioral attempts to manage (reduce or tolerate) stressful situations (Aldridge and Roesch, 2007). Coping is a process that can either improve or block adaptation and quality of life and can also affect overall adjustment to illness (Patenaude and Kupst, 2005). Coping strategies are classified into problem-focused coping (PFC) and emotion-focused coping (EFC) (Aldridge and Roesch, 2007). PFC refers to attempts at problem-solving either directed outward to alter some aspect of the environment, or inward to alter some aspect of self. PFC may include taking actions to change what is changeable, such as seeking instrumental support medical compliance, planning, logical analysis, and problem solving. In comparison, EFC is directed toward decreasing emotional distress. This may include taking action to decrease psychological distress and adapting or accepting what is unchangeable, such as: positive expectancies/optimism, coping self-efficacy, seeking emotional support, self-control, acceptance, threat minimization, seeking other rewards, religion,

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humor, relaxation, and wishful thinking (Franks and Roesch, 2006; Kopp, 2009; Rice, 2012). The majority of people use multiple strategies to cope with stressful events (Fellow, 2004). Pediatric leukemia patients require immense coping strategies to confront the physical and psychological distress as well as adjust to the illness (Kars et al., 2008). Whether a leukemic child has a normal or pathological reaction to stress depends on his/her coping capacity (Craovan and Sava, 2013), and is affected by his/her coping strategies.

Children with leukemia confront a variety of stressors, which are either controllable situations (e.g., boring hospital stays) or uncontrollable situations (e.g., treatment side-effects). Minimal literature has addressed how coping strategies are used by leukemic children during long-term hospitalization, and how coping strategies change with patient age. Understanding what separates children with good coping strategies and adjustment from those without is critical. The aim of this study was to explore the coping strategies of Chinese children with leukemia during hospitalization.

## 2. Methods

### 2.1. Design

A descriptive qualitative study design was used. The face-to-face individual, in-depth interviews with a semi-structured schedule were used to collect the data.

### 2.2. Participants

Twenty-nine Chinese children were recruited for the study. Participants met the following criteria: (1) having had a clinical diagnosis of acute leukemia for at least three months; (2) being school-aged; (3) presenting no difficulty in verbal communication; and (4) being willing to join the study. Purposive sampling was used by ward head nurses to selected and recommended participants. Participant selection was varied according to sex, age, and education level. Additionally, location of residence was varied as open discussion about cancer is considered to be taboo in rural regions and small cities in China.

### 2.3. Data collection

Data were collected in Peking University First Hospital and People's Hospital in Beijing, China. After obtaining participant and parental consents, interviews were conducted in the nurse's office. During our pilot interviews, we found parents interrupted their children or answered for them, then parents agreed to be absent from the interviews. Data were collected in private in-depth face-to-face interviews. Questions assessed participant: experiences and feelings, ways of seeking practical and psychological support, and coping strategies during hospitalization. Questions focused on coping strategies were as follows: (1) What did you do when you were depressed or upset? (2) What did you do when you were having problems with your disease? (3) When you have emotion or illness problems, which strategy do you like to adjust to your illness? Interviews were tape-recorded. Every participant was interviewed one time. Interviews lasted 35 min (range: 22–50 min) and were transcribed verbatim within 24 h. To ensure accuracy and clarify misunderstandings, a copy of the interview transcript was printed and shared with each interviewee. Printed copies were collected after three days' time; no changes were made to the initial interview transcripts. Data was collected until saturation by the first author. To establish a rapport with the participants, during the data collection period the first author performed clinical nursing duties in the ward.

### 2.4. Ethical considerations

This study was conducted following approval by the ethics committees of the university and the two hospitals. All of the pediatric participants and parents were informed about the study aim. They were also informed that the interviews would be tape-recorded, but anonymity would be maintained. Finally, they were informed that participation in the study was voluntary and they were free to withdraw from the study without any repercussions.

### 2.5. Data analyses

All interviews were transcribed verbatim by the first author. The data were analyzed using qualitative content analysis methods (Timmins, 2013). The main procedures involved: (1) breaking down data into smaller, more meaningful units; (2) coding and naming the units according to the information represented; (3) grouping coded materials based on shared concepts; and (4) deriving themes by identifying relationships between categories. The first and third author each independently analyzed the data. Research team members, including the first and third authors and their supervisor (the second author), reviewed the analyses and reached consensus through discussion and reflection. Finally, the first author collected new data in the clinical units to affirm the research findings.

## 3. Results

### 3.1. Characteristics of the study sample

Twenty-nine children were approached regarding this study, including 16 boys and 13 girls, ranging in age from 7 to 14 years, with a mean age of 12.5 (SD = 3.0). The length of time since diagnosis was 13.6 months (SD = 4.7), ranging from 5 to 21 months. Education stages of the participants included: (1) seven children (24.0%) in primary school Grades 1–2 (7–8 years); (2) 11 children (38.0%) in primary school Grades 3–6 (9–12 years); and (3) 11 children (38.0%) in Junior Middle School (13–14 years). Six participants resided in Beijing (20.7%) while 23 participants resided elsewhere (79.3%). All selected participants were eligible, and agreed to participate in the study (100% response rate).

### 3.2. Coping strategies and preferred coping style

Coping strategies were labeled as problem-focused or emotion-focused coping. Each participant used both strategies to deal with his/her suffering and low mood during hospitalization. Seven coping strategies were identified. Two were problem-focused: seeking information and problem solving. Five were emotion-focused, including: seeking emotional support, self-control, venting emotions, acceptance, and seeking rewards. Coping styles fit into three broad categories: self-dependence, dependence on professionals (e.g., nurses and doctors), or dependence on parents/caregivers.

### 3.3. Problem-focused coping

*Seeking information-* Children would seek information to understand the disease, treatments, prognoses when they were in doubt. Fifteen children aged 7–12 years said that seeking information was an important cognitive problem-focused strategy for them to eliminate their fear of the disease and treatment regimens. An 8-year-old boy said, "I like asking questions, such as the effects of drugs. My nurse talked to me and I did not feel afraid after getting more information. She told me I could be cured if I cooperated with my doctor and I could go back to school. I am very happy." He obtained

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