

# Listening to Her Voice~ Decision-Making in a Teenager With Multiple Relapses of Leukemia

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## Background & Objective

Traditionally, advance care planning (ACP) for minors relies on parents as primary decision-makers, often limiting the child's own voice. However, recent research supports allowing children and adolescents to participate in medical decision-making according to their developmental abilities, and to express their own care goals and preferences. This case presents an adolescent girl with refractory leukemia. After multiple relapses, she repeatedly requested to initiate ACP, but whose requests were declined by her parents. This study aims to illustrate how the medical team supported the patient and her family during the terminal phase of her illness.

## Methods & Interventions

The patient was diagnosed with acute leukemia at the age of 12. Despite receiving standard therapy, she experienced three relapses, and her disease remained uncontrolled after multiple courses of chemotherapy and two bone marrow transplants. At the age of 18, she expressed her wish to discontinue invasive treatments; however, Taiwanese regulations prohibit individuals under 20 years of age from signing an ACP document. In distress, she asked the medical team, **“Why is no one willing to listen to me?”**

Key approaches adopted by the medical team:

### 1. Clarifying patient values

- Fear of treatment suffering
- Quality of life concerns
- Bodily autonomy
- Desire to preserve hair

### 2. Supporting the mother

- Addressing emotional distress and grief
- Facilitating understanding of prognosis and terminal phase
- Guiding the transition from curative treatment to supportive care

## Results

Through multidisciplinary collaboration, the following outcomes were achieved:

### 1. Respecting the patient's autonomy (Figure 1)

- ❖ Chemotherapy was discontinued in accordance with her wishes
- ❖ Her body image and sense of self were preserved (long hair)

### 2. Integration of palliative care (Figure 2)

- ❖ Supported the fulfillment of her wishes (e.g., visiting a cat café)
- ❖ Provided emotional support and facilitated family communication

### 3. Home-based support

- ❖ Home visits were arranged to help her achieve personal goals and prepare for end-of-life closure

### 4. Ethical alignment (Figure 3)

- ❖ An ethics consultation was conducted to address ACP for minors
- ❖ Alignment in the care plan was achieved

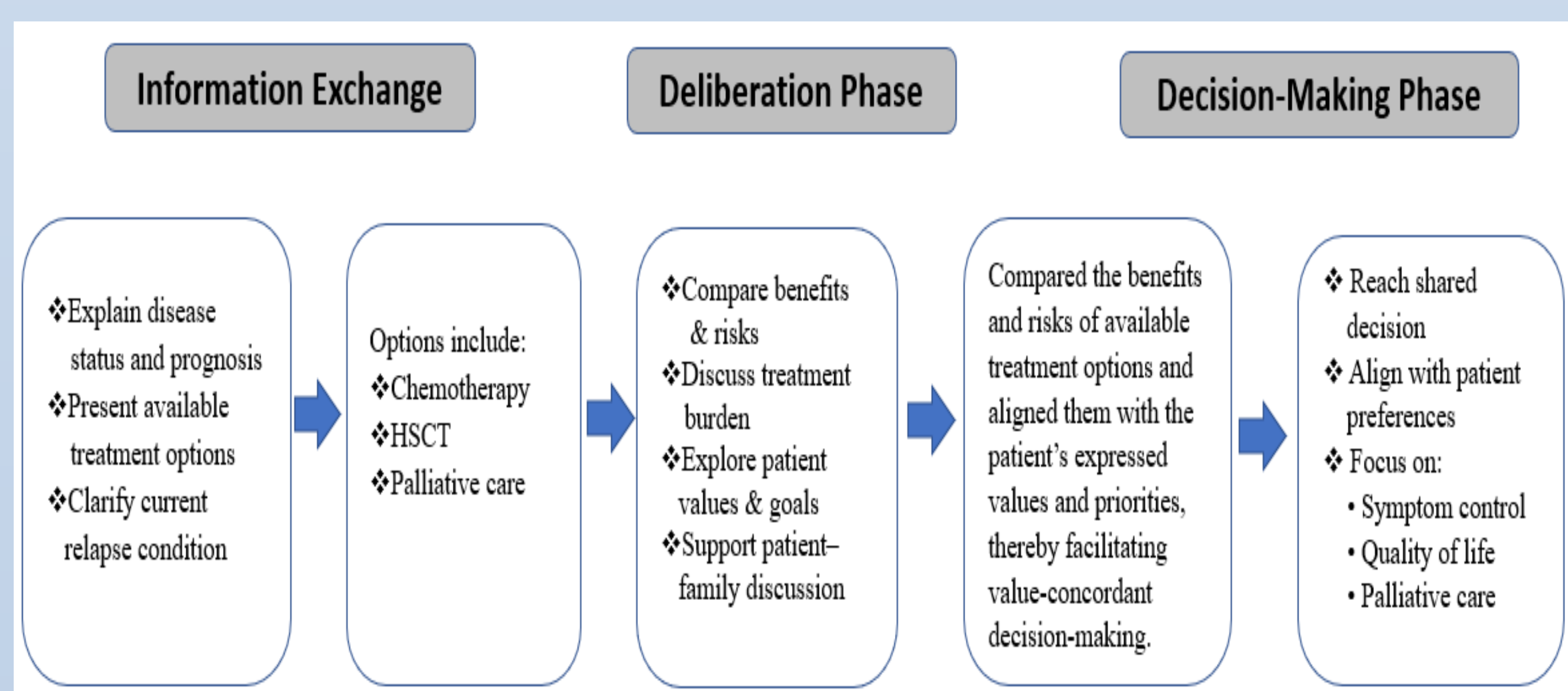


Figure 1. Three-Step Shared Decision-Making Model



Figure 2. One of the patient's wishes visiting a cat cafe



Figure 3. Clinical ethics consultation

## Conclusions

Although minors do not possess formal legal authority to make medical decisions, the medical team should nonetheless regard them as autonomous individuals and respect the values and preferences within their developmental capacity. Through consistent communication, interprofessional collaboration, and family support, dignity and health-promoting care were facilitated for children and adolescents during the terminal phase of illness.