

DYNAMICS OF EMOTIONAL REGULATION IN CHILD SURVIVORS OF CHRONIC DISEASES DURING TREATMENT: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

Fikriyah Iftinan Fauzi¹, Emma Fauziah², Maqhfirah DR³

^{1,2,3}Universitas Medan Area

Email: fikriyahiftinan@staff.uma.ac.id

Abstract

Chronic illnesses in children not only cause physical impacts but also present various psychological challenges that require emotional regulation skills during treatment. This study aims to explore the dynamics of emotional regulation in childhood leukemia survivors during treatment through an Interpretative Phenomenological Analysis (IPA) approach. The study used a qualitative approach with an interpretive phenomenological design. Participants consisted of four childhood leukemia survivors selected using homogeneous purposive sampling based on the criteria of having undergone treatment for at least six months, aged 8–17 years, and willing to participate in the study with parental informed consent and child assent. Data were collected through semi-structured interviews and analyzed using the IPA stages developed by Smith, Flowers, and Larkin. Data validity was maintained through member checking, peer debriefing, audit trails, and reflexive journaling. The results identified four main themes: (1) coping with emotional turmoil during treatment, (2) seeking comfort through social support, (3) developing independent emotional regulation strategies, and (4) building hope and meaning during treatment. The findings indicate that children's emotion regulation develops dynamically through the interaction of treatment experiences, support from family, healthcare professionals, and peers, and the child's ability to interpret the illness experience as part of the healing process. These experiences help children develop more adaptive emotion regulation strategies, increase psychological resilience, and maintain hope for the future. This research has implications for the practice of health psychology and developmental psychology, particularly in the development of psychological interventions focused on strengthening emotion regulation and psychosocial support for children with chronic illnesses during treatment.

Keywords: *emotion regulation, childhood leukemia survivors, chronic illness, Interpretative Phenomenological Analysis, health psychology.*

INTRODUCTION

Chronic illnesses in children are health conditions that last a long time and require ongoing medical treatment and monitoring. Advances in medical technology have increased the life expectancy of children with various chronic diseases, such as leukemia, thalassemia, chronic kidney disease, lupus, and congenital heart disease. However, successful treatment doesn't always come with optimal psychological adjustment. Children undergoing long-term treatment often face repeated medical procedures, prolonged hospital stays, limited activities, and uncertainty about their health, which can affect their psychological well-being (Postigo-Zegarra et al., 2024).

Various studies show that children and teenagers with chronic illnesses are at

a higher risk of experiencing emotional distress compared to kids who don't have chronic illnesses. This emotional distress can show up as anxiety, sadness, fear, feelings of helplessness, and even symptoms of depression, which are influenced by how the child perceives the threat of their illness, their self-esteem, and their family functioning (Postigo-Zegarra et al., 2024). This condition shows that chronic illnesses are not just a matter of physical health, but also a complex psychological experience for children.

When facing various medical demands, emotion regulation is one of the important psychological skills. Emotion regulation refers to an individual's ability to recognize, understand, monitor, and manage emotions that arise in order to adapt to the demands of the situations they face. Good emotion regulation skills are linked to more positive psychological adjustment, better mental well-being, and the ability to handle stress in an adaptive way (Espenes et al., 2024).

In the context of chronic illness, emotional regulation plays an increasingly important role because children have to face various experiences that can trigger negative emotions, like pain, invasive medical procedures, changes in daily activities, and uncertainty about their health condition. When children can manage their emotions in an adaptive way, they tend to adjust better to treatment and show higher psychological well-being (Espenes et al., 2024). In the context of chronic illness, handling emotions becomes more important because kids have to go through different experiences that can bring up negative feelings, like pain, medical procedures, changes in daily routines, and not knowing what will happen with their health. When they can deal with their emotions in a healthy way, they usually cope better with treatment and feel better mentally.

Besides managing emotions, quality of life is an important indicator in understanding the psychological adaptation of children surviving chronic illnesses. A child's quality of life is influenced not just by their physical condition, but also by psychological, social factors, and their ability to handle various demands of the illness. Research shows that children with chronic illnesses often experience a drop in quality of life due to disease symptoms, frequent medical care, activity limitations, and changes in their social relationships and school life (Fraser et al., 2024; Güngör & Özdemir, 2023).

In facing these various challenges, not all children show the same psychological vulnerability. Some children are able to adapt positively even when dealing with serious and prolonged illnesses. The ability to endure and bounce back from various difficulties is known as resilience. Resilience in children with chronic illnesses is understood as a process of positive adaptation that allows them to function optimally despite facing significant health stressors. Recent systematic studies show that resilience is a protective factor that plays an important role in supporting the psychosocial development of children with chronic illnesses and helps them cope with the demands of long-term treatment in a more adaptive way (van der Laan et al., 2023).

The Interpretative Phenomenological Analysis (IPA) approach allows researchers to understand individuals' subjective experiences and the meaning they give to those experiences. Through this approach, researchers can explore how children understand fear, build hope, manage sadness, and develop various emotion

regulation strategies while undergoing treatment for chronic illnesses. The IPA approach is also considered suitable for exploring complex psychological experiences that have deep personal meaning for participants.

Based on the literature review, there are still limited studies that specifically explore the dynamics of emotion regulation in children who survive chronic illnesses from their own life experiences, especially in the context of Indonesia. Most studies tend to focus more on quality of life, mental health, or parents' experiences as caregivers, so children's voices as individuals directly undergoing treatment still get relatively little attention.

Other research has found that children and adolescents undergoing treatment for chronic conditions exhibit relatively low levels of quality of life, yet still exhibit relatively good levels of resilience. These findings indicate that resilience can be a source of psychological strength that helps children maintain adaptive functioning despite the limitations imposed by their illness and treatment (Darezzo et al., 2024).

On the other hand, the experience of living with a chronic illness is a dynamic and complex process. Children not only deal with the symptoms of the disease but also experience various changes in their identity, social relationships, daily activities, and hopes for the future. The long-term transition between health and illness requires children to continuously adapt to the changes that occur throughout the treatment process. Therefore, understanding children's subjective experiences is crucial to gaining a more comprehensive picture of their psychological adaptation process (Loura et al., 2024).

Therefore, this study aims to explore the dynamics of emotion regulation in children who are survivors of chronic illnesses while undergoing treatment using the Interpretative Phenomenological Analysis (IPA) approach. This study is expected to provide a deeper understanding of children's emotional experiences and serve as a basis for developing psychological services and psychosocial interventions that better meet the needs of children who are survivors of chronic illnesses.

METHOD

This research uses a qualitative approach using the Interpretative Phenomenological Analysis (IPA) method. This approach was chosen because it is suitable for understanding individuals' life experiences in depth and how they interpret those experiences. Research participants were selected using a purposive sampling technique. The number of participants was two people. The participant selection technique used homogeneous purposive sampling. Participants were intentionally selected based on research criteria, namely child survivors of chronic diseases aged 6–10 years who were currently or had undergone treatment for at least six months, were able to communicate well, and had obtained parental consent and child assent. Participant recruitment was carried out through collaboration with a foundation that supports child survivors of chronic diseases and through the dissemination of research information on social media. Prospective participants who expressed their willingness to participate in the study then underwent a screening process based on inclusion and exclusion criteria before being identified as research participants.

Table 1. Participant Characteristics

Participant	Age	Gender	Diagnosis
P1	6 years old	Male	Leukimia
P2	9 years old	Male	Leukimia
P3	9 years old	Male	Leukimia
P4	10 years old	Male	Leukimia

Data Collection Techniques

Research data was collected through semi-structured interviews aimed at gaining an in-depth understanding of the experiences of emotion regulation in children with chronic illnesses during treatment. Semi-structured interviews were chosen because they allowed researchers to flexibly explore participants' subjective experiences while adhering to interview guidelines developed based on the research objectives and theoretical studies on emotion regulation.

Interviews were conducted face-to-face at a location mutually agreed upon by the participants and their parents, such as the participants' homes or a consultation room at a foundation supporting children with chronic illnesses. Each interview session lasted approximately 45–60 minutes. During the interview process, researchers established a comfortable relationship with the participants so that the children felt safe and free to share their experiences.

The interview guidelines focused on exploring the children's emotional experiences during treatment for chronic illnesses, including the various emotions that emerged during treatment, situations or events that triggered fear, sadness, anger, or anxiety, strategies used by children to manage these emotions, the role of parents, family, healthcare professionals, and the social environment in helping children cope with their emotional experiences, and the hopes and meanings children developed for the treatment process and their future lives. During the interviews, the researcher also used probing questions to obtain more in-depth explanations of the participants' experiences.

The entire interview process was recorded using a digital recorder after obtaining consent from the parents and participants. Furthermore, the researcher took field notes to document nonverbal expressions, the interview situation, and initial reflections that emerged during the data collection process. The interview recordings were then transcribed verbatim to ensure complete and accurate documentation of all information provided by the participants. The interview transcripts subsequently served as the basis for data analysis using the Interpretative Phenomenological Analysis (IPA) approach.

Data Analysis

The data analysis in this study used the Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). This approach was chosen because it aimed to deeply understand how children with chronic illnesses interpret their experiences of emotional regulation during treatment. The analysis was conducted idiographically, paying close attention to each case before conducting cross-participant analysis.

The first stage of analysis began with repeated reading and review of the

interview transcripts to gain a comprehensive understanding of the experiences shared by each participant. At this stage, the researcher attempted to understand the context of the experiences and engage in an immersive process with the data to capture the meaning contained in the participants' narratives.

Next, the researcher conducted initial noting, or exploratory notes, on each transcript. These notes included descriptive comments regarding the content of the participants' experiences, linguistic comments related to the use of specific language or expressions, and conceptual comments containing the researcher's initial interpretation of the meaning of the experiences expressed by the participants.

Based on the results of the exploratory notes, the researcher then developed initial themes (emergent themes) that represent the psychological meaning of each participant's experience. These themes were then analyzed to identify interconnections, resulting in the formation of superordinate themes that illustrate the dynamics of emotion regulation in each case.

After completing the analysis of one participant, the researcher repeated the entire analysis process on the transcripts of subsequent participants, continuing to treat each case as a unique and independent experience. This approach aimed to maintain the idiographic character of IPA and avoid the influence of interpretations of previous cases on the analysis of subsequent cases.

The final stage of analysis involved comparing the themes that emerged across all participants to identify patterns of similarities and differences in experiences. This process resulted in superordinate themes and subthemes that illustrate the dynamics of emotion regulation in children with chronic illnesses during treatment. The entire analysis process was conducted reflectively, considering the interrelationships between participant narratives, researcher interpretations, and the theoretical foundations used in the study.

Data Validity (Trustworthiness)

The validity of the data in this study was maintained through the application of trustworthiness principles, which include credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). To enhance the credibility of the research results, the researchers employed several strategies, namely member checking, peer debriefing, audit trails, and reflexive journaling.

Member checking was conducted by providing the opportunity for participants or their parents to review the interview summary after the transcription process was completed. This step aimed to ensure that the written information aligned with the participants' experiences and minimize misinterpretation of the interview data.

Furthermore, peer debriefing was conducted through discussions with the supervising lecturer and colleagues experienced in qualitative research and developmental psychology. These discussions aimed to obtain input on the analysis process, theme development, and consistency of data interpretation, thereby reducing the potential for subjective researcher bias.

To maintain dependability and confirmability, the researcher compiled an audit trail that systematically documented the entire research process, from participant

recruitment and interviews, data transcription, coding, theme development, and the compilation of research results. This documentation allows for retracement of the research process, thereby enhancing transparency and traceability of the analysis.

Furthermore, the researcher implemented reflexive journaling throughout the research process. The reflective journal was used to record assumptions, thoughts, emotional responses, and reflections during data collection and analysis. This reflective process helped the researcher recognize personal positions and perspectives that could potentially influence data interpretation, ensuring that the resulting interpretation remained focused on the participants' experiences.

The transferability of the research was supported by the presentation of rich descriptions of participant characteristics, the research context, and the data collection process. This enabled readers to assess the suitability of the research results for application or comparison to other contexts with similar characteristics.

RESULT

Data analysis yielded four main themes that describe children's experiences of emotional regulation during treatment for chronic illness.

Theme 1. Dealing with Emotional Turmoil during Treatment

All participants described intense emotional experiences from the initial diagnosis through treatment. Fear of medical procedures was the most frequently expressed emotion. This theme describes the emotional dynamics experienced by childhood leukemia survivors from the time they receive their diagnosis to the time they undergo treatment. All participants described the treatment process as not only presenting physical challenges but also eliciting a variety of alternating emotions, such as fear, sadness, anger, anxiety, confusion, and despair. These emotions arise in response to repeated medical procedures, changes in physical condition, limitations on activity, and uncertainty about the healing process.

The analysis showed that the emotional turmoil experienced by participants developed dynamically over the course of treatment. At the initial diagnosis, most children felt more confused and afraid because they didn't yet understand their illness. Over time, the experience of chemotherapy, repeated hospitalizations, and various medical procedures led to different emotional responses in each participant.

All participants described medical procedures as the most stressful experience during their treatment. Injections, IV drips, blood draws, lumbar punctures, and chemotherapy were the main sources of fear. The fear was not only related to the pain itself, but also to the anticipation of the procedure.

P1 stated:

"I'm afraid of going to the hospital because I usually have to get another injection."

In addition to fear, children also experienced sadness due to having to limit activities they previously enjoyed with friends.

P1 and P2 stated:

"When I arrived at the hospital, I immediately became nervous. Especially when I saw the nurses carrying needles or IVs, I felt scared because I remembered the

painful injections."

Uncertainty about my health condition also raised anxiety in some participants. In addition to fear, participants also described experiencing the loss of various activities that were previously important parts of their lives. Long-term treatment forced them to take a break from school, playing with friends, participating in extracurricular activities, and even pursuing their favorite hobbies. Changes in physical condition, such as hair loss due to chemotherapy, fatigue, and limitations in activities, also caused sadness. Some children began to realize that their lives were different from those of their peers, leading to feelings of envy, disappointment, and loss.

P3 stated:

"My body tires quickly. After just a short time playing, I feel weak, so I can't play for as long as I used to."

Interestingly, the analysis showed that the emotional turmoil experienced by children was not permanent. As their experience with treatment increased, some participants began to recognize the medical procedures they would undergo, and their fear gradually diminished. Children also began to understand the purpose of treatment and developed ways to cope with situations they considered frightening. Although negative emotions still emerged under certain circumstances, repeated experiences during treatment helped children develop the ability to recognize, accept, and gradually manage their emotions. These findings suggest that emotion regulation is a process that develops throughout the treatment journey and is influenced by personal experiences, environmental support, and the child's understanding of their illness.

P3 and P4 stated:

"Now I'm more accepting of having to go to the hospital frequently. I want to get better quickly, so I'm trying to be more enthusiastic about my diet, not buying random snacks or eating MSG".

Theme 2. Seeking Comfort through Social Support

Social support is a primary source of emotional comfort for children. Parents, especially mothers, are perceived as figures who provide a sense of security during treatment.

P1, P2, P3 stated:

"If my mom is by my side, I feel calmer."

In addition to family, healthcare professionals who demonstrate a friendly and caring attitude also help reduce children's anxiety during medical procedures. Data analysis shows that social support is a key resource helping children cope with the emotional stress of chronic illness treatment. For all participants, the presence of loved ones not only provided emotional comfort but also served as a source of strength to cope with medical procedures, changes in physical condition, and the uncertainty that accompany treatment. The social support children received came from various sources, including parents, family members, healthcare professionals, peers, and their social environment. Support from peers, both in person and through social media, helps children feel less alone in facing their illness.

Parents, especially mothers, were the figures most frequently cited by

participants as sources of emotional support during treatment. The presence of mothers provided a sense of security when children faced medical procedures that caused fear or pain. For children, a mother's presence was not only interpreted as a physical companion, but also as a place of calm, protection, and emotional support.

Children described feeling more courageous when their mothers were by their side during examinations or medical procedures. The presence of parents helped reduce anxiety because children felt they were not facing frightening situations alone. In addition to providing support during treatment, parents also played a role in calming children through physical touch, words of encouragement, hugs, and praying together before undergoing medical procedures.

These findings indicate that parents serve as a secure base, providing a sense of security, enabling children to better cope with stressful situations. In the context of emotional regulation, the presence of parents also functions as a form of co-regulation, where parents help children recognize, calm, and manage emotional responses that arise during the treatment process.

In addition to parents, other family members, such as fathers, older siblings, younger siblings, and extended family, also provided meaningful support to participants. This support took various forms, such as accompanying them to hospital check-ups, comforting them when they felt sad, providing simple gifts after medical procedures, and creating a pleasant home atmosphere during their recovery period. For some participants, the attention their families provided made them feel valued and loved despite their illness. Feeling accepted by their families helped children reduce feelings of loneliness and increased their motivation to continue with treatment until completion.

P3 stated:

"My grandmother often comes by to bring me food that I like. She says it will help me get better quickly. It makes me feel like so many people love me."

These quotes demonstrate that children interpret family support as a form of affection, acceptance, and emotional presence that provides a sense of security during treatment. For children, family care is expressed not only through support during checkups or treatment, but also through simple activities that create a positive atmosphere at home. From a science perspective, these experiences demonstrate that family relationships provide a relational space where children gain emotional comfort, reduce feelings of loneliness, and build motivation to persist with treatment.

Theme 3. Developing Independent Emotional Regulation Strategies

The analysis showed that as the treatment process progressed, participants no longer relied solely on the support of others to cope with emotional distress, but also began to develop various strategies for managing their emotions independently. The experience of undergoing prolonged treatment encouraged children to recognize emerging emotions and find the most effective ways to reduce fear, sadness, anxiety, and anger. Although the strategies used varied for each participant, they all shared the same goal: to help children feel calmer and better able to navigate the treatment process. Further analysis showed that the emotion regulation strategies developed by participants could be grouped into three

subthemes: diverting attention, reappraising the treatment experience (cognitive reappraisal), and expressing feelings to a trusted person.

One of the most frequently used strategies by participants was to distract themselves from fear and discomfort during treatment. Children tried to focus on activities they enjoyed, such as watching cartoons, playing games, drawing, reading storybooks, listening to music, or playing with siblings when their health allowed. These activities helped children focus less on pain, boredom during hospitalization, and anxiety that arose before medical procedures. For participants, enjoyable activities provided a way to create positive experiences during the often emotionally stressful treatment process. By distracting themselves with activities they enjoyed, children found their time in the hospital more manageable and their negative emotions gradually diminished.

P1 and P4 stated:

"When I'm sad, I watch cartoon videos, playing with friends, playing on cellphones, games to forget."

P2 and P3 stated:

"If I'm scared, I usually tell mom."

Relationships with peers were also an important source of support for participants. Although most children experienced limitations in face-to-face interaction due to their health conditions or treatment schedules, they still tried to maintain connections with friends through text messages, video calls, social media, and visits when their health allowed. For children, communicating with friends provided an opportunity to share stories about daily life outside the hospital. This interaction helped them distract themselves from their illness and maintain their identity as children who still had a social life like their peers. Furthermore, some participants also received support from friends who had similar experiences as chronic illness survivors. This shared experience made children feel more understood, as they could share stories about the treatment process, fears of medical procedures, and hopes for recovery. This experience reduced feelings of isolation and helped children realize that they were not facing their illness alone.

P2 stated:

"When I'm in the hospital, sometimes my friends video call me. They talk about school and hanging out with their friends. I love listening to them; it feels like I'm still with them".

These quotes demonstrate that peer relationships have a broader meaning than simply maintaining communication. For participants, interactions with friends helped maintain their identity as children who still have a social life outside the context of illness. Furthermore, support from friends who share similar experiences as chronic illness survivors provided a sense of understanding and emotional validation. From a science perspective, these experiences reflect that peer relationships provide a crucial space for children to reduce feelings of isolation, build hope, and strengthen their abilities to cope with the treatment process.

Theme 4. Building Hope and Meaning While Undergoing Treatment

The results of the analysis show that despite the various physical and emotional challenges experienced during treatment, all participants still tried to maintain hope

for the future. This hope becomes a source of motivation that helps children survive a series of long and tiring medical procedures. For participants, hope was not only interpreted as the desire to recover from illness, but also as the belief that their lives would return to the way they were before the illness. The experience of living with a chronic illness slowly forms a new perspective on life, family, health and the future.

The analysis shows that the process of building hope is a dynamic experience. At the start of treatment, most participants felt more uncertainty and confusion about the condition they were experiencing. However, as time goes by, support from family, health workers, peers, and experience of successfully going through various stages of treatment helps children build confidence that they can get through these difficult times.

All participants expressed a strong desire to return to their daily activities like other children their age. They hoped to return to school fully, play with friends, participate in activities they enjoyed, and live their lives without having to visit the hospital regularly. This hope served as a primary motivation, driving the children to persist with treatment despite the pain, boredom, and physical limitations. For the participants, recovery meant not only the disappearance of the disease, but also the opportunity to regain the freedom to live a life that had been interrupted by the treatment process.

As participants gained experience with treatment, they began to understand that each medical procedure they underwent served a purpose, helping them become healthier. Although these procedures often caused pain and discomfort, children began to understand this as a necessary part of the process of healing. This shift in how they interpreted treatment helped children reduce their resistance to medical interventions. This experience demonstrated a shift in perspective, from viewing the hospital as a frightening place to one that offered opportunities for healing. In the context of emotional regulation, positive interpretations of treatment helped children reduce anxiety and increase their preparedness for future medical procedures.

The experience of living with a chronic illness also provided an opportunity for participants to recognize their inner strengths. Several children described feeling braver, more patient, and better able to cope with difficult situations than before their illness. While the process was not easy, repeated experiences with medical procedures and the challenges of treatment made them realize their ability to persevere. Furthermore, participants began to realize the importance of maintaining their health, valuing time with family, and appreciating simple things they previously took for granted. The experience of chronic illness became part of a life journey that shaped how they viewed themselves and life more broadly.

P3 stated:

“Now I love my body more. I remember the doctor's words about eating healthy and resting to recover quickly. When I was sick, my grandmother would often defend me when I fought with my younger sibling. I was happier when everyone was home and we could eat or talk together”.

DISCUSSION

This study shows that emotion regulation in children undergoing treatment for chronic illness is a complex and dynamic process. Children experience a variety of negative emotions, particularly fear, sadness, and anxiety, which arise in response to the diagnosis, medical procedures, and limitations on daily activities.

The study findings indicate that social support plays a crucial role in children's emotion regulation. The presence of parents not only provides emotional comfort but also serves as a source of co-regulation, a process where adults help children manage their emotions. This finding aligns with theories of emotional development, which emphasize the importance of children's relationships with primary caregivers in developing emotional regulation skills.

In addition to relying on social support, children also demonstrated the ability to develop independent emotion regulation strategies. The strategies identified in this study included distraction, positive thinking, and expressing emotions to trusted individuals. These strategies demonstrate the use of emotion regulation that focuses on shifts in attention and cognitive appraisal, as described in Gross's model of emotion regulation (Aldao et al., 2015; Gross & Thompson, 2007; J. J. Gross, 1998, 2015; J. J. Gross et al., 2006; J. J. Gross & John, 2003; M. M. Gross, 2024; John & Gross, 2004; Pankewycz et al., 2023).

Another interesting finding is the emergence of meaning-making processes during the treatment journey. Children not only sought to reduce negative emotions but also developed hopes and goals in life that helped them persevere through various challenges. The hope of recovery, returning to school, and carrying out activities like other children is an important source of psychological strength.

CONCLUSION

This research shows that emotional regulation in children undergoing treatment for chronic illnesses occurs through four main processes: coping with emotional turmoil during treatment, seeking comfort through social support, developing independent emotional regulation strategies, and building hope and meaning around the illness experience. Children's emotional regulation abilities are influenced not only by internal factors but also by the support of family, healthcare professionals, peers, and spiritual beliefs. Therefore, pediatric healthcare services need to address psychological aspects and provide psychosocial support that can help children develop adaptive emotional regulation during treatment.

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