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Experiences of Parents in Providing Care and Support to their Children with Cancer While Striving for Resilience in East Kalimantan: A Qualitative Study

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ABSTRACT

Background: Childhood cancer is a life-changing experience for both the child and the parents. Uncertainty about the health condition, fear of losing their child, the high demand on time and energy for ongoing care, and financial burdens can lead to considerable stress on parents and their ability to provide optimal care for their child. Adequate resilience is needed to help parents to cope and adapt to the situations they are dealing with. Exploring how parents of children with cancer deal with the different phases of feelings and challenges while caring for their child will help care providers, especially nurses, identify appropriate interventions to help parents stay resilient. **Methods:** This is a qualitative study that employs a phenomenological approach to explore the experience of resilience among parents who are caring for their children with cancer. The study involved 11 mothers whose children were receiving treatment at a cancer referral hospital in East Kalimantan, Indonesia. Participants were selected using a purposive sampling technique, and semi-structured interviews were conducted individually with each participant. Thematic analysis was employed for data analysis. **Results:** Three themes emerged from the interviews: the adverse impact on parents, their endeavours to regain strength, and the fluctuating emotions encountered during the adaptation process. **Conclusion:** Attaining resilience involves traversing challenging phases, which are characterised by both moments of strength and vulnerability. The support they receive from their immediate community proves invaluable in helping parents adapt to evolving circumstances, enabling them to fulfil their roles as carers and provide optimal care for their children.

Keywords: Cancer; Child; Parents; Resilience

INTRODUCTION

Cancer in children can have an impact on physical and psychological conditions, not only in children but also in parents. Parents who have children with cancer have a psychological response that varies from the child diagnosed with the disease to if the child gets treatment. Parents' responses include crying, denying, feeling guilty, fear of losing their child, trying to find the best care, and being the best parent for their child (van Oers *et al.*, 2014; Mariyana & Betriana, 2021). During cancer treatment, children experience symptoms due to treatment side effects and disease progression, have frequent hospital visits, and are in periods of recovery and relapse. All these conditions put parents under constant stress, as they are the primary carers in health care (Harding *et al.*, 2015).

Caring for a child with cancer can take a lot of energy and focus from parents, and their lives can change dramatically. They must spend so much time with their sick child that they sometimes forget to care for themselves and reduce their usual social activities (Pishkuhi *et al.*, 2018). Parents are always there for their children and play an important role in their upbringing. When a child suffers from an illness, the parent's duty to

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care for them will increase because they must pay more attention to get maximum care. Therefore, it is imperative to pay attention to the well-being of parents both physically and psychologically so that they can provide maximum care for their sick children (Mendenhall & Mount, 2011).

Resilience is not only about how a person survives but also about how they can adapt positively and return to the state where they can live well (Walsh, 2016). Resilience is crucial for parents who have children with cancer because by having resilience, parents can gain personal strength to adapt optimally to the changes faced (Rosenberg *et al*., 2013). The resilience process requires strength and the ability to get through difficult situations. Parental resilience in childcare is a process that requires knowledge, skills, support, and experience to provide quality care or care to their children (Gavidia-Payne *et al*., 2015).

Research to explore how parents can achieve resilience is still limited in Indonesia. Many studies have been conducted to explore parents' experiences of caring for a child with cancer, not specifically to explore how parents become resilient (Martawinarti, Oktaria & Andini, 2023; Pusmaika *et al*., 2020; Rokhaidah & Herlina, 2018; Wijayanti & Astuti, 2021). Other studies have explored parental resilience but have been limited to parents of children aged 1-5 years (Tumanggor & Dewi, 2022). Some studies identify the resilience of parents who have children with cancer, but the study used a quantitative design (Hanik Fetriyah, Yuliana & Susanti, 2024). From 2021 to 2022, there were 3834 cases of childhood cancer in Indonesia spread across eleven public hospitals (Indonesian Paediatric Centre Registry, 2023). Parental resilience can be an intriguing research topic. Indonesia's cultural and religious diversity shapes unique family dynamics, with traditional families emphasising togetherness and spirituality that influence parental resilience. In addition, East Kalimantan has only one referral hospital for childhood cancer, and the number of cases continues to rise. Limited facilities force parents to travel long distances and find temporary accommodation, adding to their psychological stress.

Caring for children with cancer is part of nursing care that not only focuses on fulfilling physiological needs but also psychological, social, and spiritual needs. Empowering parents as caregivers is critical, and understanding their resilience will help nurses design supportive interventions. This study aimed to explore the resilience of parents caring for a child with cancer.

METHODOLOGY

Participant and Design

This study used a qualitative phenomenological approach within a constructivist paradigm that focuses on the subjective nature of reality and how individuals create meaning from their personal experience and social interaction. This research was conducted at a cancer institute in East Kalimantan, Indonesia. Participants were parents of children with cancer (aged 0-18 years) who were willing to share their experiences. Inclusion criteria required parents to be the primary caregiver, to speak Indonesian, and to have a child diagnosed with any cancer type. Participants were recruited through coordination with the hospital and cancer centre to arrange interviews. 11 mothers participated in this study, with the number determined based on achieving data saturation without any new meaningful findings ((van Manen, Higgins & van der Riet, 2016; Vasileiou *et al*., 2018). No fathers were included due to the distances from the treatment centre and their shared responsibility of caring for siblings. Mothers primarily accompanied the child during cancer treatment (Spiropoulos *et al*., 2023). All participants provided consent by signing the informed consent form.

Data Collection

Data were collected through 40- to 60-minute interviews in the Indonesian language. Data collection was conducted for eight weeks between the second and third week of December 2022 and the first week of March 2023. The interviews were audio-recorded, and the researcher noted the mother's expressions and behaviours. The interview guide focused on parents' feelings after their child's cancer diagnosis, their adjustment strategies, and challenges in parenting, and the questions were developed based on resilience theory. Resilience theory describes the process of a person becoming resilient, from facing unexpected situations to building adaptability (Hurd & Zimmerman, 2010).

Data Analysis

The recordings were transcribed after the interviews were completed. Data were processed using Colaizzi's method (Colaizzi, 1978; Fain, 2020). The stages of data analysis in the Colaizzi method are reading the transcripts repeatedly, extracting significant statements related to the phenomenon, giving meaning to each statement, grouping similar statements into themes, and writing a complete description for each theme. To ensure the trustworthiness of the data, the researcher used several strategies, including credibility by discussing the data and conducting member checking to verify the interview results, dependability by evaluating the transcripts and analysing them with the team, and transferability by describing the results in detail and in context (Korstjens & Moser, 2018).

Ethical Consideration

This study has received ethical approvals from Research Ethics Committee, University Technology Mara, Malaysia, with reference number REC/02/2023(PG/MR/42) on 9th February 2023 and the Health Research Ethics Committee, registered under reference number 85/XI/KEPK-RSKD/2022 on 28th November 2022.

RESULTS

The study included 11 mothers between the ages of 28 and 46 whose children had all been diagnosed with leukaemia. Regarding educational level, one mother had an elementary school education, three had a junior high school education, five had a high school education, and one each had a diploma and a bachelor's degree. The children ranged in age from 2 to 13 years, and the duration of treatment ranged from 3 months to 8 years. Table 1 illustrates the summary of the participants' characteristics.

Table 1: Characteristics of Parents and Children

Participant	Age of parents	Educational Level	Age of Children	Sex of Children	Diagnosis	Time Since Diagnosis (Months)
Parent 1	45	Diploma	10 years	Female	Leukaemia	17
Parent 2	39	High school	11 years	Male	Leukaemia	96
Parent 3	28	High school	7 years	Male	Leukaemia	48
Parent 4	46	Bachelor	13 years	Female	Leukaemia	3
Parent 5	35	Elementary school	3 years	Male	Leukaemia	5
Parent 6	35	Junior High school	10 years	Male	Leukaemia	29
Parent 7	42	Junior High school	6 years	Female	Leukaemia	24
Parent 8	29	High school	11 years	Male	Leukaemia	12
Parent 9	30	Junior High school	2 years	Female	Leukaemia	5
Parent 10	32	High school	5 years	Female	Leukaemia	24
Parent 11	40	High school	3 years	Male	Leukaemia	12

Based on the thematic analysis of the interview results, three themes were identified: 1) the adverse impact on parents, 2) the endeavour to regain strength, and 3) the fluctuating emotions encountered during the adaptation process.

Theme 1: The adverse impact on parents

This theme describes the changes that mothers experienced after their children were diagnosed with cancer, including psychological and physical impacts. Psychologically, mothers felt emotions such as devastation, disbelief, crying, fear, anger, sadness, shock, and confusion, both at the time of the initial diagnosis and while accompanying the child. Some participants even felt that their child's illness was the result of their mistakes as parents.

"...my feelings were shattered. It felt as though the sky was descending upon me. At that time, Leukaemia—this blood cancer—was something we were still unfamiliar with. We were laymen, did not understand it, and had no clear picture of what it entailed. So, if you ask about my feelings, I do not even know how to describe them. They were all mixed up at that time..." (Parent 1, child aged 10 years)

"...I was sad and shocked. How could this happen? The disease affects children, and my child is only two and a half years old. I was very angry inside, but I could only express it in unclear words..." (Parent 2, child aged 11 years)

"... It is a mixed feeling. I want to cry. My husband cried too, and I cried as well. Even now when I tell my story, I feel like crying. I can't—I just cannot find the words..." (Parent 5, child aged 2 years)

"... I cannot believe it. It feels so unacceptable. But what can I do? That day was overwhelming—I did not even know how to describe my feelings. I was sad and immediately shocked, thinking, 'No way, hopefully not...' in my heart..." (parent, 7; child, 6 years old)

In addition to the psychological impact, participants experienced physical complaints such as loss of appetite, weight loss, headaches, and sleep disturbances while caring for their children.

"...I do not have an appetite, so I decided to fast. Sometimes my friends ask, 'Why don't you ever eat? Don't you ever drink?' I tell them I'm fasting because I simply cannot eat. Just imagine, when my son was first diagnosed, I weighed 59 kilograms, but now I'm down to 45 kilograms..." (Parent 1, child aged 10 years)

"... The first time, I did not eat regularly. I felt like I just wanted to lie down. My head was dizzy because I was so focused on my child that I did not have time for myself. I had no appetite..." (Parent 5, child aged 2 years)

"… I often cannot sleep because I keep thinking, how will my child be? Will he recover?" (Parent 9, child aged 2 years)

Theme 2: Endeavour to regain strength

This theme describes mothers' difficulties in caring for their children, with the time to accept their child's condition varying from 2 to 8 months, although crying often occurs when remembering their child's pain. Mothers went through this process by praying, supporting each other, playing games to distract themselves, thinking positively, and organizing their lives. Support from spouses, family and friends through visits or phone calls was also a source of strength.

"...I try to be patient, patient, and more patient. The most important thing is prayer. I believe in the power of prayer. In our religion, Islam, there is the practice of praying in the middle of the night, waking up to pray during those hours..." (Parent 1, child aged 10 years)

"...After meeting friends, we share and support each other. That's when we realise, we are not alone. There are others, just like our children..." (Parent 2, child aged 11 years)

"...I am grateful that there are friends who encourage me. Some send prayers, while others provide information about alternative medicine..." (Parent 10, child aged 5 years)

"...Even though he is far away, my husband always calls. Sometimes, when he has a day off, he comes here to see our son and me..." (Parent 11, child aged 3 years)

Theme 3: Fluctuating emotions encountered during the adaptation process

This condition illustrates the changes in the mother's emotions affected by the child's condition. Sometimes, mothers feel down with disappointing test results or sad news, but at other times, they feel calmer when they see other children who are also struggling or when their children eat and go back to school.

"...What makes us retreat is thinking about the future. We immediately worry about what's ahead. My child is a girl, and I fear no one will want to be with her. I wonder what she can do with this condition. Her father and I have already made plans. Maybe she will not go to school; perhaps we will start a business instead. I sometimes think like that, but then I remind myself not to think too far ahead. Let us just focus on getting through this chemo first. After that, we'll think about the Bone Marrow Puncture (BMP). We approach the procedure step by step. Sometimes, I'm the one who overthinks and gives solutions, so I ask my questions and then answer them myself..." (Parent 1, child aged 10 years)

"…I'm afraid that if my child suddenly has a fever, I worry about what that means. I'm really scared that she might have to repeat therapy…" (parent 3, child aged 7 years)

"…Being separated from my husband and children is tough. My body is here, but my mind is in Berau (the name of the city where the mother lives). I feel like: How can I not take care of my child? My 4-year-old still needs a mother's love. It has been a year since I have been there for him…" (parent, 6; child, 10 years old)

DISCUSSION

The results of this study show the process that parents go through in accepting the change in their child's health. As a result, they struggle to cope and make every effort to survive. The findings of this study are discussed in relevance to the facts and results of previous related studies on parents' experiences in caring for children with cancer.

The Adverse Impact on Parents

Since their child was diagnosed with cancer, parents experienced a range of mixed feelings, such as sadness, crying, anger, and other psychological symptoms. Research conducted by Rahmani *et al*. (2018) showed that parents who have children with cancer experience high anxiety and depression. When a child is sick, it is not simple for a mother to go through the process. They cannot express things, such as what they feel or think. In addition, at the same time, they must remain a strong figure for their children so that everything can go well Ruslan, Satiadarma & Subroto, 2021. Every mother will experience emotional and psychological responses when her child is diagnosed with cancer. This is due to the unexpected information mothers receive about their child's condition, which can be traumatic and lead to responses such as fear, surprise, sadness, unpreparedness, denial, and a sense of helplessness (Olagunju *et al*., 2016; Shattnawi *et al*., 2021).

In general, the response shown by parents when their child is diagnosed with cancer is shock, fear, and uncertainty about their child's condition (Jackson *et al*., 2007). In the treatment phase, the child and family face uncertainty, side effects, and relapse. During treatment, both children and their parents find that their personalities and behaviours often change positively and negatively (Mardakis *et al*., 2019). The distress experienced by parents not only affects their psychological well-being and ability to care for their children but also affects their interactions with their children, where parents become more emotional towards their children, which triggers their children's non-compliance with medication and triggers stress and anxiety in their children (Okado *et al*., 2016; Prussien *et al*., 2018; Riba *et al.*, 2019).

Endeavour to Regain Strength

It is not always impossible for parents to cope with the emotions of raising children. It's hard, but they can strengthen their spiritual lives through prayer and trust in God and learn to be strong by supporting each other and other parents going through similar experiences. Parents also continue to try to think positively.

A positive and optimistic attitude is essential in increasing parental resilience (Luo *et al*., 2022). A sense of optimism helps parents cope with and adapt to stressful changes in their circumstances. With a high sense of optimism, a person can control the impact of life stressors (Fayed *et al*., 2011). Parents with high resilience are more confident and skilled in caring for their sick children than those with low resilience. Other factors that can improve parental resilience are financial, spiritual, and support (Luo *et al*., 2022; Peterson *et al*., 2014). Having high hope and spiritual well-being, as well as high resilience, can increase parents' inner strength and reduce anxiety and depressive symptoms (Koyu *et al*., 2024; Liu *et al*., 2023). Problem-solving strategies that address stressors directly can lead to effective solutions. Stress coping skills help parents of children with cancer cope with their stress symptoms (Phiri *et al*., 2023). Training designed to develop problem-solving skills has been shown to help alleviate symptoms of stress and depression experienced by mothers of children with cancer (Sahler *et al.*, 2013). Activating social support is one way to help people deal with adversity and has been shown to reduce stress (Samios *et al*., 2020). In this study, parents expressed their happiness in a supportive community where they shared their spirits, cooked, and comforted each other. The value of unity in Indonesian culture encourages helping each other, which gives them the strength to stay strong even in sadness. Kalimantan, inhabited by various tribes, including Dayak, has strong cultural and religious values that strengthen the sense of community even without blood ties. These values, including spirituality, are a source of strength for parents to overcome difficulties and build resilience. Parents who have adequate resilience when caring for their child with a chronic illness can help reduce the occurrence of physical and emotional exhaustion (Cici & Özdemir, 2024).

Fluctuating Emotions Encountered During the Adaptation Process

Everyone has a different response to adversity; some experience long-term disruption, some experience minimal disruption, and some do not take long to return to normal (Troy *et al*., 2022). In this study, all parents said that even though they had been accompanying their children through treatment for a long time and had adapted to changes in their children's conditions, there were times when they became sad again, stressed again, and wanted to give up. However, they become strong again when they see positive things happening to their children, such as good laboratory results and mild post-chemotherapy symptoms, and when they gather with other parents.

Parents who have children with cancer have a high level of unmet needs, which include psychosocial, emotional, physical, informational, financial, educational, and spiritual needs. The results of research conducted by Lewandowska (Lewandowska, 2022) show that psychological, emotional, and informational needs are the most needed by parents of children with cancer. When a child is sick, new needs arise, such as ensuring that the child gets the best conditions, which requires the family's ability to adapt (Wiener *et al*., 2017). Providing family support by taking time to listen to their concerns and hopes for their child's condition can help families through the difficult times they are experiencing (Petersson *et al*., 2023).

Our findings suggest that nursing practitioners, particularly paediatric nurses, can develop interventions to help parents become resilient and adapt to changing situations. The findings show that in becoming resilient, parents find several strategies to help them cope with stressful situations. Providing emotional and psychosocial support to parents is necessary to make them more energised to live their days while caring for their child with cancer. Parents who received emotional support from their partners and family felt less psychological distress (Melguizo-Garín *et al*., 2021). The findings also suggest that in paediatric nursing practice, nurses can apply family-centred care to deliver nursing interventions to help maximise care for children. Family-centred care practices can strengthen parents' beliefs about their ability to handle parenting challenges and care for ill children (Margaretha *et al*., 2021; Harrison *et al*., 2021). In addition to providing social support, the findings suggest that nurses should actively provide parents with information about cancer childcare, including what they need to improve. Providing adequate and relevant information can increase parents' knowledge and skills and help them overcome parenting and childcare challenges. In addition, nurses demonstrate a trusting attitude toward parents' abilities by encouraging parents to take an active role in their child's care (Salvador, Crespo & Barros, 2019).

Finding out that their child has a serious illness is a difficult situation for parents. The treatment and care process does not always go smoothly. Parents push themselves to get up and deal with the problem, even if it is not always ideal. This study uniquely highlights the importance of peer support systems within the cancer community, emphasizing their role in enhancing resilience for children with cancer and their parents, a perspective rarely discussed in previous research.

Limitation

This study had limitations, including potential researcher bias in data interpretation and recall bias affecting participant responses. Future research should use longitudinal designs for real-time insights and incorporate diverse perspectives to enhance understanding. Exploring culturally specific resilience strategies may also improve support for affected families.

CONCLUSION

Resilience is a process that develops over time through various stages. Resilience is a gradual process that develops over time. Participants' experiences show that parental resilience is not achieved all at once but through a cycle of emotional ups and downs. Although they were devastated when their child was diagnosed, they tried to accept and live with the reality. The treatment process and uncertainty often brought back stress, but support from partners, family, friends, and faith gave them the strength to persevere. Seeing the child play and eat well is the main motivation. The availability of cancer community houses where parents can share their experiences can strengthen this process. The study showed that some parents who had been with their children for a long time still experienced periods of stress, while others remained optimistic despite the diagnosis. This suggests that resilience is a process that takes work and may be different for everyone. Future studies need to focus on care interventions to improve parents' resilience by designing programs that meet their needs.

Recommendation

Based on this study's findings, it is recommended that more research focus on strategies to improve the resilience of parents of children by implementing resilience-enhancing programs such as resilience skill training, which includes stress management or maintaining optimism for parents who have children with cancer. In addition, it is recommended that communities supporting cancer patients be responsible for setting up activities to improve caregivers' resilience.

Conflict of interest

The authors declare that they have no competing interests.

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