Quality of Life of Families Caring for Preschool Children with Acute Lymphoblastic Leukemia undergoing Chemotherapy: A Qualitative Descriptive Study

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Abstract: Childhood cancer presents as a significant and life-threatening illness that profoundly impacts the well-being of the entire family of the affected child throughout the trajectory of the disease. This qualitative descriptive study explored strategies to improve family quality of life according to the perspective of families of preschool children with acute lymphoblastic leukemia undergoing chemotherapy. Data were collected from March to June 2019 through in-depth individual interviews with 32 family members aged 20-50 years from the outpatient hematology department and pediatric ward. Content analysis was used for data analysis which revealed three themes:

1) Modification of family function: they needed adjustment of family roles, preparing family caregivers for cancer care, and maintaining family interactions; *2) Effectiveness of family communication:* there were contents, methods, and information sharing; and *3) Social support for family caregiving,* including external and spiritual support.

Findings could help nurses and other health providers identify and promote potentially effective strategies to improve the quality of care and the quality of life of patients and families. The findings also provide valuable insights for nurses to develop interventions to enhance and promote the reorganization of family roles to take of the child with leukemia, as well as chemotherapy treatment communication in the family and support for family caregiving.

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Introduction

Pediatric cancer is a paramount health concern in Thailand and across the world[1,2] and is the second-leading cause of death for children under 14.[3] Annual incidence rates of diagnosed cancer are between 50 and 200 per one million children globally[2] and approximately 106.2 per million person-years in Thailand.[1] Acute lymphoblastic leukemia (ALL) is the most common cancer type in children, representing about 20% of childhood cancers globally.[4] The highest incidence of childhood leukemia occurs among the first 2-5 years of age, comprising one-third of the pediatric cancer cases in Thailand.[1] Chemotherapy is currently the most efficient therapy for ALL in children.[5] Advances in the successful chemotherapy treatment strategy have significantly increased the five-year survival rates for newly diagnosed pediatric ALL to more than 80%.[6,7] Throughout childhood cancer, health conditions affecting children are severe and life-threatening. These illnesses bring about significant life changes and profoundly impact the well-being of the affected child's parents and the entire family.[8] Throughout childhood cancer, health conditions experienced by children represent significant life changes and have a profound impact on the well-being of the affected child's parents and the entire family unit.

Families encounter various lifestyle challenges that disrupt the family structure, strain family functioning, increase the economic burden, and cause psychological difficulties.[9,10] The cancer diagnosis and treatment of children significantly impact family interaction and communication. Additionally, the results of many studies showed that childhood cancer impacts children's physical and mental health and reduces the quality of life (QOL) of family members.[11,12]

Family quality of life (FQOL) is increasingly being recognized as a useful criterion to assess the impact of cancer treatment, as ALL is a lifelong chronic disease. Preschool children with ALL frequently experience changes in their immediate environment due to their illness and chemotherapy treatment, significantly impacting the family unit and dynamics. In addition, the entire family unit is affected when a member becomes ill, necessitating adaptation to new expectations.[11] However, only a few studies have focused on the FQOL of children with ALL, mainly in Western countries.[11,12] Until now, no research has been done on Thai families with preschool children undergoing chemotherapy for ALL.

Therefore, understanding the strategies for improving FQOL according to the perspective of all family members related to their child's care and the chemotherapy treatment process requires comprehending an essential program for a family of preschool children with ALL undergoing chemotherapy. Therefore, a qualitative method was conducted to provide rich and in-depth information. The aim of this study was to explore strategies to improve FQOL according to the perspective of families of preschool children with ALL undergoing chemotherapy. The results of this study can be used to provide appropriate nursing care and develop effective family interventions to improve the FQOL in children with ALL in Thailand.

Conceptual Framework

The concept of FQOL has been used since the 1970s, and different definitions of FQOL have been proposed. Family quality of life (FQOL) is a multidimensional life domain that examines the family as a whole. The theory and model of FQOL highlights the dynamic interaction between the family as a unit and individual family members.[13] As an extension of individual quality of life (QOL), FQOL includes at least four core domains concerning health and a variety of physical, emotional, and social dimensions and other domains related to the impact of diseases and health, such as spirituality, finances, and the environment.[14]

According to the literature, numerous factors affect FQOL. Family coping and family interactions were strongly correlated with FQOL, according to previous studies focusing on family-related factors.[11] Research has also investigated the relationships between FQOL and family income, the family's function, emotional support, and family interaction and communication patterns.[15,16] Over time, these issues may significantly affect the QOL and care of the child.[17]

Several studies about QOL are mainly from the perspective of preschool children, parents or primary family caregivers rather than from the perspective of the family members. Although parents or primary family caregivers usually play key roles in caring for preschool children with ALL, other family members are related to caring and chemotherapy treatment, influencing the child's life, and taking care of children.[11,17]

The findings of studies include that the FQOL of children with chronic illness has increased.[18,19] Most evidence has shown the published focused on FQOL of children with intellectual disabilities, developmental delays, or specific diagnoses, such as autism spectrum disorder (ASD) or Down syndrome.[14,18] However, no existing studies in this area have focused on FQOL of children with cancer.[20] Nevertheless, few previously published studies have concentrated on the individual level rather than the family level.[21,22]

No study can be found that has developed strategies to improve FQOL according to the perspective of families of preschool children with ALL undergoing chemotherapy through a qualitative lens. Previous research has concentrated on enhancing FQOL, but improving this in families of children with ALL who are undergoing chemotherapy in the Thai context has not been studied. Moreover, most previous studies on childhood cancer' in Thailand focused on increasing cancer knowledge. Still, they neglected to address the critical problem of FQOL to establish family-level for addressing children with cancer care needs.

Study Aim

To explore strategies to improve family quality of life, according to the perspectives of Thai families of preschool children with ALL undergoing chemotherapy

Method

Study Design: This study is part of a larger project which utilized an exploratory mixed-method design to explore strategies to improve FQOL according to the perspective of families of preschool children with ALL undergoing chemotherapy. The qualitative descriptive phase of this study is reported here, and the method offers a comprehensive summary of an event in everyday terms of those events.[23] This report followed the Consolidated Criteria for Reporting Qualitative Studies (COREQ): a 32-item checklist to improve the quality of reporting.

Study Setting and Participants: This study was conducted in the outpatient hematology department and pediatric ward at a provincial hospital in Eastern Thailand. Purposive sampling was used to recruit informants, and the inclusion criteria included: (1) All family members of a preschool child aged 3-5 years diagnosed with ALL and older than seven years, (2) involved in the caring and chemotherapy treatment process of their child for not less than one month, (3) the child had not developed an infection or switched to other treatments, and (4) being able to read and understand the Thai language. Semi-structured in-depth interviews were undertaken with 21 families of preschool children with ALL undergoing chemotherapy (n = 32). The sample size was reached when data saturation occurred, and no new information was generated.

Ethical Considerations: The Ethics Review Sub-Committee approved the study protocol for Research Involving Human Research Subjects of Thammasat University, Thailand (COA No. 030/2563), and the hospital's (COA No. 014/2563) research ethics committee in May 2017 before study implementation. All participants were informed about the purpose, process, methods of this study and possible risks and benefits of participating in this research. Participants had opportunities to ask or refuse to answer questions and withdraw study participation at any time. All participants signed a voluntary research agreement form and permitted the audio recording of interviews. Code numbers and pseudonyms were used to ensure anonymity.

Data Collection: This study was conducted in March-June 2019 by the principal investigator (PI), who received skills training in qualitative data collection and analysis. The PI approached the patients and their families while waiting for a pediatrician at the outpatient hematology department and admission to the pediatric ward. The interviews lasted between 30 to 45 min, and consent to be audio-recorded was obtained. Participants were given opportunities to ask questions or provide additional information at the end of the interview. The interview guide consisted of five open-ended questions developed by the researchers after an extensive and intensive literature review and the concept of FQOL of Zuna and colleague[13] (see **Table 1**). This interview guide was used to explore the family strategies for improving FQOL. In addition, in-depth semi-structured interviews in Thai were conducted with at least two to three family members in each family. They shared their needs for maintaining the FQOL in their way. Questions asked included: *Since your child was diagnosed with cancer and began chemotherapy treatment, how was the situation in your family? What were the major changes in your family? How did the way of life in your family change in terms of the family role, family interaction, family communication and family emotional support?*

Table 1. Interview guide

Item	Questions
1	Since your child was diagnosed with cancer and began chemotherapy treatment, how was the situation in your family? What were the major changes in your family? How did the way of life in your family change in terms of the family role, family interaction, family communication and family emotional support?
2	Have those changes you mentioned had an impact on your family? And how?
3	How did your family deal with the problems? In your opinion, did those methods make your family successful in dealing with those problems? What problems were your families still unable to deal with? Why is your family unable to deal with them?
4	In terms of making the family of the child with ALL undergoing chemotherapy be stable and strong, how did your family need help and support? Or, in your opinion, what should the family do in a situation like this?
5	What should be the role of a nurse or healthcare professional to help increase the family's quality of life?

Data Analysis: The interview data were transcribed verbatim in Thai and analyzed at the family unit level using content analysis, following Creswell's approach.[24] This involved coding, categorizing the codes, and defining themes as part of the analysis process. The PI transcribed, read, reread, and studied the dialogues several times to determine meaningful sentences. Subsequently, meaning units were extracted based on the latent meanings behind them using a coding process and creating groups by comparing the codes in terms of similarities and differences. Overall themes emerged after comparing the categories and considering latent meanings.

Rigor and Trustworthiness: Subsequently, the PI worked with a research team to obtain a deeper understanding of each perspective and use the Criteria of Trustworthiness for the Qualitative Inquiry to evaluate the trustworthiness and rigor of the qualitative research, as well as the trustworthiness methods described by Lincoln and Guba.[25] Credibility was established by active participation in building a connection with the families and spending time in family activities. The PI conducted member checking by discussing the interpretation reports with three participants in this study. Transferability was produced by providing a thick description of information relevant to the context and participants. Dependability and confirmability were verified through an audit trail. Finally, a research supervisor evaluated the processes and outcomes of the study to decide whether the data supported the findings, interpretations, and conclusions.

Findings

Data were collected from 32 family members, of whom more than half (62.50%) were female and ranged from 20 to 50 years of age, with a mean age of 33.81 ±7.95 years. More than half (53.13%) were mothers, and most (96.88%) were married. Their education level ranged from being illiterate to attaining an undergraduate degree. More than half had a high school education (53.13%). Most participants (31.25%) were employed and had a monthly family income of 10,001-20,000 baht (40.63%) (approx. USD 288-576). As shown in **Table 2,** more than half of the preschool children with ALL (66.67%) were boys and ranged from 3 to 5 years and eight months of age. The duration from diagnosis to chemotherapy treatment (42.86%) ranged from 12 to 15 months and an average of 10 months (see **Table 2**).

Table 2. Demographic characteristics of the family members and preschool children

Demographic data	**Family members (n = 32)**		**Demographic data**	**Preschool children (n = 21)**	
	Number	**%**		**Number**	**%**
Sex			Sex		
Male	12	37.50	Boy	14	66.67
Female	20	62.50	Girl	7	33.33
Age (year)			Age (year)		
(Mean = 33.81, SD = 7.95, Range = 20-50)			(Mean = 4.30, SD = 1.09, Range = 3-5)		
20-30	15	46.88	3y-3 y 11 mo	9	42.86
31-40	9	28.13	4y-4 y 11 mo	5	23.81
41-50	8	25.01	more than 5 y	7	33.33
Marital status			Duration from diagnosis to chemotherapy		
Married	31	96.88	treatment (month)		
Single	1	3.13	(Mean = 10, SD = 3.62, Range = 12-15)		
Family relation			4 mo-7 mo	7	33.33
Father	12	37.50	8 mo-11 mo	5	23.81
Mother	17	53.13	12 mo-15 mo	9	42.86
Relative	3	9.38			
Educational level					
Illiterate	1	3.13			
Elementary School	4	12.50			
High school	17	53.13			
Bachelor’s degree	10	31.25			
Occupation					
Cultivators	7	21.88			
Employee	10	31.25			
Government official	1	3.13			
Housewife	7	21.88			
Private business	1	3.13			
Merchant	6	18.75			
Family income [baht /(USD) per month]					
5,000-10,000 ($144-287)	10	31.26			
10,001-20,000 ($288-576)	13	40.63			
> 20,001 (> 577$)	9	28.13			

Table 2. Demographic characteristics of the family members and preschool children (Cont.)

Demographic data	Family members (n = 32)		Demographic data	Preschool children (n = 21)	
	Number	%		Number	%
Number of family members					
3	10	31.25			
4	14	43.75			
5	8	25.00			
Length of patient care (month) (Mean = 9.91, SD = 3.60)					
12 or less	18	56.26			
> 12	14	43.75			
Universal health coverage					
Civil servant medical benefit scheme	2	6.25			
Universal coverage scheme	30	93.75			

Three major themes emerged from interviews with family members: (1) Modification of family function, (2) Effectiveness of family communication and (3) Social support for family caregiving. **Table 3** delineates the overall themes with representative participant quotes.

Theme 1: Modification of Family Function

This theme focused on how families alter roles, responsibilities, and day-to-day functioning to accommodate the needs of preschool children with ALL and other family members. They changed the role of family members together and supported their necessary roles for childcare. Child illness induced an imbalance in the child and family's life, which caused families to reorganize and change their roles. Moreover, providing other family members with cancer care and reducing possible side effects of chemotherapy treatment were considered necessary.

Subtheme 1.1: Adjustment of Family Roles

Family members in this study reported assigning a role to each family member. The mother was the main caregiver of the sick children, and the father was the only one who worked to earn money for the family. The family changed their daily activities and lifestyle from the time of diagnosis and throughout the treatment process. A family member stays at the hospital with the child with ALL. Most of the family reported that other members attempted to rearrange and maintain a normal life as much as possible; for example, they changed the duty of caring for the child at the hospital to allow the mother or primary caregiver some rest.

> *"During the first six months of chemotherapy, my child must be hospitalized for about ten days at a time. In our family, we consulted together to change our duties. I decided to quit my job to take care of our child, both at the hospital and when she returned home. The husband is responsible for all family expenses."* (Mom 5)

> *"After knowing the treatment plan that during the first six months, the child would have to be hospitalized for about ten days at a time, I had my wife quit her job to take care of the sick child. I was in charge of managing family expenses and taking care of my older brother."* (Dad 5)

Subtheme 1.2: Preparing Family Members for Childcare

Families prepared other family members, such as a grandmother, grandfather, and the eldest child, to provide cancer care for the sick child or training for managing cancer in order to assist with caring for children when the primary caregiver was absent from the home. There was an assignment of responsibilities for caring for sick children to other family members. Moreover, in almost all families, sick children received more attention. The family became more responsible as a whole. Everyone was involved in preparing for the care of a child receiving chemotherapy at home. They prepared together information about the child's treatment, monitoring for possible side effects of chemotherapy treatment and contact information for the child's health care team.

> *"Another duty of everyone in the family that added is planning and preparing together for child care at home. We have five people living in the house. There were parents, an older sister, a sick child, and a grandmother. When I was absent from the home, my husband and my mother can take care and take care of doctor's appointments."* (Mom 3)

> *"When my daughter is not at home, I can take care of my grandson, such as food preparation, hand washing regularly and avoiding contact with other infected children and adults. And if the daughter has to go to work on the day of the doctor's appointment, I can take my grandson to the doctor's appointment." (Grandmother 3)*

Subtheme 1.3: Maintaining Interaction in the Family

Family interaction changes occurred in the first month after the children were diagnosed with ALL. During a child's treatment for cancer, the primary caregiver felt a loss of interaction with their spouses, healthy child or other family members, and a loss concerning their daily life activity. The strength of some families was trying to maintain family interaction as before the child had cancer. Other family members try to spend time visiting their sick child at the hospital and using time together. Some families place the importance of maintaining affection and appreciation in the family. When the families focused on strong relationships, they talked about sharing positive emotions, showing caring, being nice to each other, and giving each family member a chance to express their feelings.

> *"Sometimes I feel that our family has a better relationship with each other than ever before. My husband always spends time with me and my sick child when he gets off work. He will come back home to have dinner together. He spoke kindlier than before. He asked me, "Are you tired?". He let me rest, and he will take care of our child."* (Mom 20)

> *"My child's illness is an event that causes stress and anxiety for family members. So I will try to spend time after work caring for my sick child so that my wife can rest. My wife and I spend more time together, for example, eating together and talking more. It makes me feel that our family has a better relationship than before."* (Dad 20)

Theme 2: Effectiveness of Family Communication

Direct communication was essential for effective problem resolution during stressful events in the family. Effective communication is the process of exchanging ideas, information, or messages between family members through a selected method to the receiver with a purpose that can be understood with clarity. Effective communication within the family was important because it enabled members to express their needs and concerns about childcare, such as how to care for their child undergoing chemotherapy and how to prevent the side effects of chemotherapy.

Subtheme 2.1: Direct Communication to Create Mutual Understanding

More than half of the family discussed problems honestly and needed open communication within the family. They were encouraged to share opinions, ideas, and concerns, both positive and negative. Open sharing or open communication can create a mutual understanding in the family and develops cooperation and strong relationships. More than half of the family always communicated with their family members about the child's prognosis and chemotherapy treatment. Speak up when something is unclear or confusing. Make sure they understand important information. Some of the family communicated by offering examples and sharing reasons for the child's treatment and care, including why the child needs chemotherapy and how to prevent infection and bleeding. Some of the family stated that active listening, paying attention, and respecting other family members' opinions create a positive atmosphere that allows them to express their different thoughts and discuss what should be done in a child ALL undergoing chemotherapy.

> *"Is the disease curable? is the first question asked by family members. The next question is how to treat it. I try to communicate with family members to understand and be encouraged that it can be healed. The child must be treated with chemotherapy. It takes about 2-3 years. During treatment, side effects of chemotherapy might occur. It is something that family members need to take care of their children."* (Mom 8)

> *"Everyone in the family should be aware of how to avoid complications when the child comes back home. If everyone in the family is on the same page, they may take care of the child to prevent side effects, such as prevent infection and be careful with toys and sharp objects to prevent bleeding. "* (Dad 8)

> *"When a problem comes up in my family, we shouldn't run away from our problems. We should face them head-on. We try to talk all things together and open communication to each other in order together find a solution."* (Mom 2)

> *"When talking, the family must attend and listen to each other, not interrupt and listen to the end first in order to know what the other person wants to convey and try to speak with understanding."* (Dad 2)

Subtheme 2.2: Information Sharing for Maintaining Family Care

Most participants reported that they had spent time communicating within the family to provide information and knowledge about the child's treatment care, including details on the current treatment and symptoms when discharged from the hospital or after visiting a doctor. Most participants also stated that there was more than one caregiver in their family. They spent time communicating within the family to share their child's symptoms data (e.g., fever, bleeding, fatigue, and nausea and record to use it in the next follow-up). They needed to share information on how to care for their child undergoing chemotherapy and how to prevent the side effects of chemotherapy, such as infection, bleeding, anemia, nausea and vomiting.

> *"There are many family members who take care of children. Therefore, we must talk and ask about the symptoms of the child and share about current treatment and complications. Because it helps everyone to know the symptoms of the child and what must be a precaution.* (Mom 10)

> *"After discharge from the hospital or after visiting the doctor, my wife always shared the information about treatment, such as what medicine our child received, how our child stayed at the hospital, are there any complications, and if there was anything that needed special care?"* (Dad 10)

Theme 3: Social Support for Family Caregiving

In the families' experiences, social support was a strategy that could reduce the family's negative impact and benefit their ability to cope with stress. Most families received social support from a variety of sources, including the healthcare provider, a relative, and other families with experience of a child with ALL care. The findings found two main support subthemes that influence families of preschool children with ALL daily life, including external and spiritual support.

Subtheme 3.1: *External Support*

Social support outside the family was important and included personal, emotional, and financial support. The health status of the child assessed by the healthcare provider during cancer treatment was essential and useful information. More than half of the family stated that clear information about the child's condition and chemotherapy treatment from healthcare providers was important for family members to understand the reality and the treatment plan, could be applied in children's care and communicated with other family members. Some families benefitted from the experiences and information shared by other families, helping them provide good nutrition, prevent infection, and manage common health problems during chemotherapy treatment. Moreover, talking with other families in situations like theirs helped ease stress, anxiety, and loneliness. Some received support from other family members or close relatives, such as grandparents helping to care for another healthy child at home or their mother-in-law dealing with some housework. Emotional support was an essential component of cancer care for enhancing the psychological functioning of families coping with cancer and their preschool-age children. We found that family was the primary and most important resource of emotional support. Most participants mentioned maintaining a positive attitude toward cancer in their children. Positive thoughts could reduce distress, help with coping with stress and the ability to live more effectively. Strategies for maintaining positive thinking and positive emotions helped buffer against stress, such as positive expectations, attitude, and hope.

> *"Try to find good points or positive points from the cancer situation that occurred in the family. When the child is sick, everyone in the home takes care of each other and shows how much someone loves our family. I told myself that it was going to be ok and that I could pass this problem. In addition, we think that our children still have hope of treatment. Other children can still be cured; our child can be cured too."* (Mom16)

> *"In addition to information about treatment and care obtained from doctors and nurses. We get more information about a child's care from the parents of a child who has ALL and received chemotherapy, like my boy. It greatly reduces anxiety, fear, and stress. Moreover, me and my family are more confident about the treatment and care of our boy."* (Dad16)

Subtheme 3.2: *Spiritual Supporting*

In pediatric cancer, the whole family's life is affected, and parents may turn to spirituality and focus on positivity to cope with fear and powerlessness. In the Thai Buddhist context, religious belief is one of the most essential aspects of spiritual support. More than half of the participants described spirituality as a unique personal belief that gives strength to life. Religious or Thai Buddhist support was integrated with the body and mind and a factor that helped increase resilience.

> *"My religious beliefs help me overcome any problem. When I have problems, I go to the temple to pray and make a wish for my son to recover from illness. If my son heals from his illness, I will go to ordain. The belief and faith in Buddhism gives our family more peace of mind and gives us energy."* (Mom 7)

> *"Asking for blessings from the Buddha, chanting, making merit, and meditating are ways to strengthen the mind for myself and my family. And I believe that the positive energy that family members receive from praying will result in sick children getting better."* (Dad 7)

Discussion

This study revealed the perspectives of Thai families of preschool children with ALL undergoing chemotherapy attempting to improve the FQOL. Most participants paid attention to preparing the family for childcare. Interview data provided strategies for improving the quality of life in a family, including modification of family function, the effectiveness of family communication, and social support for family caregiving.

The diagnosis of ALL in a child disturbs the family's functional balance since it occurs in a family system, causing adverse effects on all its components. Therefore, most families needed support to change their organization to adapt to the challenges they faced over time. A family member usually stayed at the hospital with a sick child. Therefore, one of the family members had to resign from their job.[9] Moreover, family members attempted to rearrange and maintain a normal life as much as possible. They focused on changing the roles of family members together, supporting these roles in the child's care and sharing responsibilities. The findings of this study align with those reported elsewhere,[10,11] indicating that enhancing the functioning of families with a child diagnosed with cancer and providing support in the reorganization of their roles are crucial health and treatment priorities. Previous research has also emphasized the significance of managing daily activities and the need for practical assistance in tasks, such as cooking and caring for siblings. This includes managing the primary caregiver's relaxation and achieving a sense of normalcy.[40]

When a sick child returns home, families need to be prepared for childcare. Taking care of sick children is hard work. Primary caregivers may feel isolated and may not be able to perform this role forever. Therefore, helping family members get information and support is important.[41,42] In this study, everyone was involved in preparing for the care of a child receiving chemotherapy at home. They prepared together information about the child's treatment, monitoring for possible side effects of chemotherapy treatment and contact information for the child's health care team. A study[42] indicated that families of children with cancer need access to accurate information concerning their child's condition to actively engage in healthcare activities. To make informed decisions together regarding the best approach for their child's care, it is essential for them to have access to clear and comprehensible information.[42]

During a preschool child's treatment for ALL, changes in the family's interaction occurred. In this study, the strength of some families was trying to maintain family interaction as they were before the child had cancer and maintain affection and appreciation in the family. This positive impact of strong relationships in the family is relevant to another study[32] where parents of children with cancer stressed the importance of maintaining relationships and effective communication with their family members. When parents maintain close and trusting relationships with other family members and children throughout the child's care, they feel rewarded.

In regard to the effectiveness of family communication, all participants reported that direct communication in the family is important for effective problem resolution, and it enables members to express their needs and concerns about childcare. They communicated in order to share information regarding ALL and chemotherapy treatment knowledge of their child. This knowledge allowed families to get involved in childcare. These findings align with existing international studies, suggesting that identifying decision makers, providing thorough explanations during the decision-making process, respecting the family's knowledge of their child, and engaging in clear and timely discussions about prognosis are associated with reduced long-term parental grief and improved QOL.[33,34] Similarly, open communication within a family of a child with newly diagnosed cancer influenced their daily life and created a positive environment to care for the child with cancer.[28]

In addition to the content of family communication, they also reported on the importance of open, clear, and positive communication that helps the family maintain the QOL. This method of communication can create a positive atmosphere and lead to collect interpretation and understanding within the family.[28,33]

This finding was correlated with another study,[33] reporting that parents of children with cancer's perception of care quality correlated with communication quality within the family, including compassionate, caring, honest, and prognostic conversations. Likewise, the parents focused on the impact of their child's disease on future QOL and considered prerequisites for improved care.

Besides direct communication, information sharing is essential for maintaining family care. Most of the families in this study needed to communicate to share information regarding how to care for their child undergoing chemotherapy and to prevent the side effects of chemotherapy. As evidenced by prior research, families need to understand the cancer, the chemotherapy treatment, and hospitalization while maintaining hope.[41] Moreover, families reported that they had spent time communicating within the family to share their child's symptoms data. Family members have stated that if the information was given little by little, they could not understand it very well and desired to know a summary of leukemia information as the overall big picture.[40]

Regarding external support for family caregiving, the finding was partially supported by the central aspects of FQOL for cancer patients and their families.[26] The results from another study[26] reported central aspects of FQOL had no mention of social support as external support, but that it had a direct effect on FQOL via family perspective. This finding aligns with another study[27] that indicated that having social support networks from family, friends, and governmental or non-governmental institutions served as a protective factor for families. Similarly, another study[28] stated that social support perceived by family caregivers of children with newly diagnosed cancer influenced their daily life, open communication, and creating a positive environment to care for the child with cancer.

Cultural differences in the family may cause different perspectives on disease care. In Thai culture, the family is an extended family in which the grandparents live together. Therefore, some families are supported and cared for by their grandparents or relatives, while many Western families living together are nuclear in nature. Moreover, Thai relatives or grandparents offer to provide some financial support to families.[29] Similarly, the results of this study showed that certain families received support from other family members, such as grandparents, who assisted in caring for another healthy child at home.

External support emerged among those family members who had the assistance of preschool child care. The findings found external support that influences family daily life by creating a positive environment to care for the child with cancer. More than half of the families stated that the information from health care providers could be applied in the care of children and communicated with other family members. The results of this study were similar to two others[35,36] that indicated introducing educational interventions to provide information and support for caregivers of children with cancer can enhance their confidence in caring for their child and improve their overall QOL.

Moreover, families received benefits from the experiences and information shared by other families who had the same child's care experience but were more experienced in this. When they talk with other families, they feel less stressed, anxious, and lonely. These sub-themes were supported by previous studies.[32,37] It is critical that parents-family of other children with the same cancer diagnosis and receive chemotherapy treatment support.[32] When their child was in the hospital, meeting the parents of other children and those who had gone through psychosocial problems and were more experienced helped them become much more relaxed and get more child information in addition to those received from healthcare professionals.

In the Thai context, Buddhist doctrine and Buddha's teachings have influenced people's way of life, beliefs, and spirituality. Thai Buddhist beliefs include those about prayer, merit-making and the Law of Causes and Effects.[30] Spirituality is associated with a personal belief, reflecting spiritual hope, an individual's mindset, personal experience, and quality of life.[31] This study indicates that spirituality is a unique personal belief that strengthens to family life and is one of the factors that help increase resilience in a child's cancer situation.

Preschool children with ALL can cause psychological problems and emotional stress; most participants reported that they tried to support their family members' emotions to maintain a positive relationship in the family. These findings align with previous research, which has reported that emotional support from family members is linked to improved FQOL.[37] Research has also demonstrated that when caregivers of children perceive greater emotional support from their family, it leads to various benefits, including improved quality of life, enhanced relationships, and reduced psychosocial risks.[38]

In addition, the presence of ALL caused economic impact, further exacerbated by parental loss of income. Families with greater support needs and lower social support present greater economic impact.[9,39,43] To relieve the socioeconomic exhaustion of the family, financial support from other family members and relatives enabled our participants to strengthen themselves in childcaring. This was confirmed by a family of a child with cancer[9] who stated that social support and financial support assumed an important role in the decrease of the economic needs caused by the disease.

In conclusion, the participants in this study showed their ability to collaborate and provide care for their loved ones through their perspectives and strategies. They effectively managed care situations, modified family functioning, maintained a balance within the family, communicated effectively, and received social support. These findings have important implications for improving FQOL and guiding the development of future interventions targeted at families of preschool children with cancer undergoing chemotherapy.

Limitations

This study was conducted in a specific Eastern province, highlighting its unique cultural context. Consequently, the findings may not be representative of other parts of Thailand or different perspectives within the family context. Further studies conducted in diverse backgrounds could potentially offer different insights and strategies to enhance the family quality of life.

Conclusions and Implications for Nursing Practice and Research

This study's findings highlight the important strategies to improve FQOL in the care of preschool children with ALL undergoing chemotherapy. Thirty-two interviews were analyzed, and the findings were discussed. The results demonstrated that family members faced several challenges while caring for their child. Thai families of preschool children with ALL undergoing chemotherapy described the strategies that maintain improving the FQOL. Further research needs to understand the context and need of caring in each family to tailor interventions or family-based programs for a family of preschool-age children with ALL to improve the FQOL. Moreover, this result study will provide a basis for further research focusing on the effectiveness of the family-based program for improving FQOL or other caregiver groups of childhood cancer patients and for other chronic diseases with a life-threatening illness. The findings can help nurses and other health providers identify and promote potentially effective strategies to improve the quality of care and the quality of life of patients and families. These strategies should include promoting the reorganization of family roles to take of the child, ALL and chemotherapy treatment communication in the family and support for family caregiving.

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คุณภาพชีวิตของครอบครัวดูแลเด็กวัยก่อนเรียนที่เป็นมะเร็งเม็ดเลือดขาวเฉียบพลันชนิดลิมโฟบลาสต์ที่ได้รับการรักษาด้วยยาเคมีบำบัด : การศึกษาพรรณนาเชิงคุณภาพ

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บทคัดย่อ: โรคมะเร็งในเด็กถือเป็นโรคที่สำคัญและคุกคามถึงชีวิตที่มีผลกระทบต่อความเป็นอยู่ที่ดีของทั้งครอบครัวของเด็กตลอดระยะการดำเนินของโรค การศึกษาพรรณนาเชิงคุณภาพนี้เพื่อค้นหากลวิธีในการเพิ่มคุณภาพชีวิตครอบครัวตามมุมมองของครอบครัวที่ดูแลเด็กวัยก่อนเรียนที่เป็นมะเร็งเม็ดเลือดขาวเฉียบพลันชนิดลิมโฟบลาสต์ที่ได้รับการรักษาด้วยยาเคมีบำบัด เก็บรวบรวมข้อมูลระหว่างเดือนมีนาคมถึงเดือนมิถุนายน พ.ศ. 2563 โดยการสัมภาษณ์แบบเจาะลึกรายบุคคลในสมาชิกครอบครัวอายุระหว่าง 20-50 ปี จำนวน 32 คน จากแผนกโลหิตวิทยาและหอผู้ป่วยนอกเด็ก วิเคราะห์ข้อมูลด้วยการวิเคราะห์เนื้อหา และสรุปได้ 3 ประเด็นหลัก

1) การปรับการทำหน้าที่ในครอบครัว ประกอบด้วย การปรับบทบาทในครอบครัว การเตรียมครอบครัวในการดูแลเด็กโรคมะเร็ง และการรักษาปฏิสัมพันธ์ในครอบครัว 2) การสื่อสารที่มีประสิทธิภาพ ประกอบด้วย เนื้อหาที่ใช้สื่อสาร วิธีการและการแบ่งปันข้อมูล และ 3) การสนับสนุนทางสังคม ประกอบด้วยการสนับสนุนจากนอกครอบครัวและด้านจิตวิญญาณ

การค้นพบสามารถช่วยพยาบาลและผู้ให้บริการด้านสุขภาพอื่น ๆ ระบุและส่งเสริมกลยุทธ์ที่มีประสิทธิภาพในการปรับปรุงคุณภาพการดูแลและคุณภาพชีวิตของผู้ป่วยและครอบครัว การค้นพบของการศึกษานี้ให้ข้อมูลเชิงลึกที่มีคุณค่าสำหรับพยาบาลเพื่อพัฒนาโปรแกรมในการเพิ่มคุณภาพชีวิตครอบครัวของเด็กก่อนวัยเรียนที่เป็นมะเร็งเม็ดเลือดขาวเฉียบพลันชนิดลิมโฟบลาสต์ที่ได้รับการรักษาด้วยยาเคมีบำบัด รวมถึงส่งเสริมการปรับโครงสร้างบทบาทของครอบครัวเพื่อดูแลเด็กป่วย การสื่อสารการรักษาด้วยเคมีบำบัดในครอบครัวและการสนับสนุนสำหรับการดูแลครอบครัว

Pacific Rim Int J Nurs Res 2023; 27(3) 585-600

คำสำคัญ: มะเร็งเม็ดเลือดขาวเฉียบพลัน การดูแล ยาเคมีบำบัด เด็ก ครอบครัว วัยก่อนเรียน คุณภาพชีวิต การศึกษาพรรณนาเชิงบรรยาย

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