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Exploring the beliefs of caregivers about the caregiving experiences of children with acute lymphoblastic leukemia in Malaysia

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Abstract

Background: Cancer is one of the major leading causes of childhood death, and the most common type is acute lymphoblastic leukemia. The survival rate has increased in recent years; however, the long patient trajectory may trigger psychological distress among caregivers as they play an active role in ensuring that the child's basic needs are met. Being in a patient-focused system, the needs of caregivers may be neglected.

Objective: This study aimed to explore the caregivers' beliefs on children with acute lymphoblastic leukemia caregiving experiences in order to promote their well-being.

Methods: Caregivers from thirteen families of children with acute lymphoblastic leukemia participated in this phenomenological study. NVivo 12 was used for the thematic analysis of the data. Consolidated criteria for reporting qualitative research (COREQ) were used in this study.

Results: Overall, five main themes for caregivers' beliefs were identified from their responses: 1) dietary intake with emphasis on its importance in aiding recovery and its potential influence on cancer complications, 2) childcare which emphasized the need to be strong and self-sacrifice, 3) treatment which reflected the use of home or natural remedies and caregivers' negative perception towards chemotherapy, 4) causes of cancer believed to be linked to early childcare choices on food, beverage, and stress imposed on the child, and 5) source of beliefs that included doctors, online platforms, personal encounters and information on food labels.

Conclusion: Caregivers' beliefs are varied and nuanced, formed in a multicultural social background of Malaysia. These findings provide knowledge for future supportive cancer care for patients, their caregivers, and the treatment outcome in the Malaysian context. Nurses, who play an essential role between healthcare professionals and patients and/or their caregivers, can be empowered to provide psychological support, early detection of psychological distress, and exploration of caregiver beliefs, given that the number of clinical psychologists in Malaysia is lacking, and there is greater preference for care to be provided by doctors or nurses.

Keywords

child; caregivers; psychological distress; nurses; Malaysia; leukemia

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Background

Cancer is one of the major leading causes of death among children (Kazak & Noll, 2015; Nurhidayah et al., 2020). The most common form of cancer is Acute Lymphoblastic Leukaemia (ALL) (Keene, 2010). A similar trend was also found in the Malaysian context, where childhood leukemia accounted for a majority (82.85%) within the year 2007 to 2011 (National Cancer Institute, 2018). Nevertheless, advancements in medical treatment over the years have resulted in a tremendous increase in childhood cancer survival rates (Howlader et al., 2013). In Malaysia, the 5-year overall survival of children with standard-risk, ALL was relatively high

at 86.6% (Hamidah et al., 2009). Given the high prevalence and survival rate of ALL (National Cancer Institute, 2018), resources need to be allocated to ensure that proper child care is present in its management.

Besides the biological perspective of managing cancer, it is also important to address the psychological and social aspects of a pediatric cancer diagnosis. These aspects would eventually impact the lives of every member of the family system (Nurhidayah et al., 2020). Rait (1989) viewed the experience through the lens of the family systems approach, where psychological support is provided to the family members of children with cancer. Previous studies focusing on the psychosocial impact of chronic illnesses on the family

reflected an increase in parental psychological morbidities such as traumatic stress (Clawson et al., 2013; Kazak et al., 2005; Pöder et al., 2008), depression (Chen et al., 2020; Norberg et al., 2006; Yamazaki et al., 2005), and anxiety (Santacroce, 2002; Wijnberg Williams et al., 2006; Yeh, 2002). Consequently, a high rate of poor family functioning was reported even after treatment had ended (Alderfer et al., 2009).

Studies drawing on the perceptions of pediatric oncology families indicate that although it was a struggle, caregivers had a strong desire to resume the normal lifestyle they once had prior to their child's diagnosis (Earle et al., 2007; McGrath, 2002; Van Schoors et al., 2018). Parents felt that their responsibilities were stretched and had difficulty meeting the needs of family members when they had to fulfill the additional task of caring for the ill child (Hocking et al., 2014; Van Schoors et al., 2018). These parents needed a safe space to vent their frustration and seek support from others who have had the same experience (Hocking et al., 2014; McGrath, 2002; Mostert et al., 2008). As most caregivers were unsure of the causes of cancer, information about the course of illness was important to them (Bettle et al., 2018; Kristanti et al., 2021; Mostert et al., 2008). A majority (86%) of parents in Indonesia indicated that they required more information from their doctors (Mostert et al., 2008). However, one study showed that families tended to direct the causes of cancer towards environmental factors and the quality of early age childcare (Kohlsdorf & Costa Junior, 2012).

On the other end of the spectrum, caregivers drew on their personal experiences managing disease-relevant areas such as pain. They preferred non-pharmacological strategies as the first line of intervention (Bettle et al., 2018). Especially in the Asian context, many caregivers engaged in complementary and alternative medicine (CAM) as a supplement to conventional treatment (Ariff & Beng, 2006; Hamidah et al., 2009; Lim et al., 2006; Mostert et al., 2008). This may be fueled by their belief that natural substances used in CAM are less harmful (Ariff & Beng, 2006). In addition, the belief that food and beverage such as spirulina, vitamins, and herbal teas can facilitate recovery may be more prevalent in Asia as diet is essential to the culture (Hamidah et al., 2009). Diet is also generally associated with the survival rates of children with ALL (Barr et al., 2016).

Cross-cultural differences may exist as previous studies were mostly conducted in Western countries. This may affect the belief system of individuals living on different borders of the world. The Health Belief Model (Hochbaum et al., 1952) posits the idea that an individual's perception of the threat of an illness coupled with the belief about the effectiveness of the recommended behavior (s) will contribute to the likelihood of engaging in the behavior. Hence, the belief system is an important area to consider in treatments or interventions. Compared to adult cancer patients, a study indicated that the rarity of childhood cancer might impose limitations on studying homogeneous cancer subgroups in-depth (Kehm et al., 2018). Similarly, qualitative studies on caregivers in Malaysian pediatric oncology have received less attention. Therefore, this study aimed to address these gaps by exploring the beliefs of caregivers about the caregiving experiences of children with ALL in hopes of facilitating supportive care for these individuals and their families.

Methods

Study Design

The phenomenology approach was used to emphasize the first-person perspective and provide meaning to lived experiences (Merriam, 2009). Inductive probing was used in this approach and also provides the opportunity for clarification and allows the interviewee to share their story without constraints (Guest et al., 2011). These are essential qualities to consider in this initial need assessment phase to gather insights that guide the development of an intervention tailored to specific needs.

Participants

The respondents were caregivers of children with ALL (below 18 years old, at least six months post-diagnosis, and were still attending hospital follow-ups). In addition, caregivers fluent in either Malay or English were selected for this study. The exclusion criteria were caregivers of children in hospice care and caregivers who were being treated for psychiatric illnesses or undergoing psychological intervention. Purposive sampling was used to select the respondents.

Data Collection

The data was derived from the exploratory phase of our study that assessed the psychosocial needs of ALL caregivers in a Malaysian hospital throughout the year 2020. Participants who met the inclusion criteria were selected and invited for an interview, either in person at the hospital or through a phone call. For in-person interviews, it is noteworthy to mention the presence of non-participants consisting of the child with ALL and their siblings. All the participants were approached by the researcher (ACSS), who introduced herself as a clinical psychologist and postgraduate student at the hospital, and they had no prior contact before that. The interview was semi-structured following an interview guide tested for face and content validity through joint review by an expert in qualitative research (CMHC) and clinical psychology (MA). All participants were given information sheets on the purpose and description of the study and gave their written informed consent. The interview sessions were conducted in either English or Malay, and the duration lasted 20 to 60 minutes per interview. They were audio-recorded using a mobile device, transcribed, and translated (from Bahasa Malaysia to English). During transcription, field notes were added. The process of transcription and data analysis were done simultaneously until data saturation was reached. A repeated interview was conducted for three participants to obtain further insight into some of the key points mentioned.

Data Analysis

Thematic analysis was used in data analysis (Braun & Clarke, 2006; Creswell & Creswell, 2018). The process of organization and preparation for data analysis was done by transcribing interviews that were typed out on a computer and later exported to NVivo 12 by QSR International. The researcher (ACSS) then read the transcripts to gain a general idea and made related notes on the transcripts, which later contributed to the generation of codes. These codes led to the generation of themes. The initial themes were reviewed by an expert in qualitative research (CMHC) and clinical psychology (MA),

and revisions were made accordingly. The final themes that were generated are supported by subthemes and evidenced by key quotes from multiple interviewees. The themes were driven by the research questions and emerged primarily from data analysis using thematic analysis. According to Guest et al. (2011), thematic analysis is compatible with phenomenology as both approaches are aimed at providing meaning to people's subjective experiences.

Rigor

Data analysis was performed by the interviewer (ACSS). Validity was then assessed by the level of agreement on the categorization of themes and translation between two subject-matter experts in psychology (MA, CMHC) through member checking. Information that was not in the agreement was either corrected, reorganized, renamed, or removed. Our study met 29 out of the 32 consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Ethical Consideration

This study was approved by the Research Ethics Committee of Universiti Kebangsaan Malaysia (JEP-2019-447). Informed consent was obtained from each participant before the commencement of data collection. The researchers explained the objectives and the procedures of the study and ensured that the participation in this study was voluntary and with no penalty.

Results

Caregivers from 13 families participated in this study with no dropouts. Most of the primary caregivers were females ($n = 11$, 85%). Specifically, they consisted of mothers ($n = 10$, 77%), fathers ($n = 2$, 15%) and a grandmother ($n = 1$, 8%). The age of primary caregivers ranged from 26 to 58 years old ($M = 38.62$, $SD = 8.67$), and most of them had a secondary school qualification ($n = 9$, 69%). While one of the parents had remarried (8%), more than half ($n = 9$, 69%) remained married, whereas the remaining were either divorced or separated. Four families had no secondary caregivers, and most secondary caregivers were fathers ($n = 7$, 54%). The age of secondary caregivers ranged from 27 to 46 years ($M = 37.44$, $SD = 6.33$). Similarly, more than half of them had a secondary school qualification ($n = 6$, 67%) and remained married ($n = 9$, 60%). Descriptive statistics of the children indicated that most of them were male ($n = 10$, 77%). Their age at diagnosis ranged from 2 to 12 years old ($M = 5.54$, $SD = 3.02$) and time since diagnosis ranged from 0.67 to 7 years ($M = 2.80$, $SD = 1.91$). The families were predominantly Malay ($n = 10$, 77%) and Muslim ($n = 11$, 85%). They were mostly from low income (B40 category; $n = 11$, 70%) and lived in a nuclear family ($n = 8$, 62%).

The beliefs of caregivers were organized into five themes, as illustrated in Figure 1. The first theme discusses the belief of caregivers that adequate dietary intake is key to recovery and how food can fuel cancer complications. The second theme discusses the belief of caregivers to put on a strong front and the sacrificial element in caregiving, and the third theme highlights the belief about using natural/home remedies to facilitate recovery and the negative effects of chemotherapy. The fourth theme talks about caregivers' beliefs about the

choice of food and stressors as possible causes of cancer. These beliefs were traced back to information, as the final theme, provided by the doctor, online platforms, personal encounters, and nutritional information on food labels.

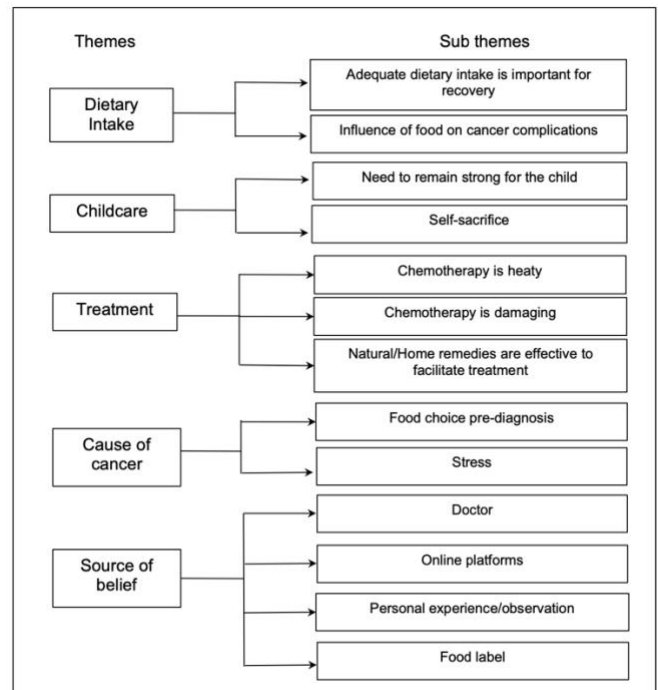


Figure 1 Summary of the themes

Theme 1: Dietary Intake

Adequate dietary intake is important for recovery

Throughout the interview, most caregivers highlighted the importance of food in facilitating their child's recovery. They perceived that consuming an adequate amount of food is vital to the improvement of their child's condition. Therefore, caregivers did their best to ensure that this was met.

"Okay, so far, her condition is getting better because number one is to take care of her diet la." (Mrs. MF, 45 years old)

"As long as we follow his appetite. He wants this, ah, we follow la. Doesn't matter, as long as he is willing to eat." (Mrs. FR, 38 years old and Mr. HN, 43 years old)

Some caregivers also held the belief that food buffered the effects of treatment in facilitating recovery.

"Need to take care of the child's diet, just force him to eat, he needs to be strong. With chemo or what, he can withstand." (Mrs. W, 43 years old)

"So need to drink lots of water because if the body doesn't get enough water, later, our, our body that doesn't get enough water will get heaty." (Mrs. MF, 45 years old)

Influence of food on cancer complications

Caregivers observed food as a medium for contagion or infection that may lead to cancer complications. This was particularly relevant when caregivers themselves were not fully in charge of preparing their child's food or when the food had been out of sight at any point of time during the period of preparation to consumption. Therefore, caregivers took extra

precautions in managing the food (including beverages) for their children.

"Because (I'm) afraid that if he simply eats outside, scared that his blood will be infected, can get the fever." (Mrs. W, 43 years old)

"...if there are leftovers, cannot keep and it cannot be, for example, after she drinks water and then, she places it on the table because maybe there, there will be bacteria that we may not be able to see right..." (Mrs. MF, 45 years old)

Sugar was identified to be the culprit for the malignant transformation of cells in the children's bodies. Hence, they actively tried to minimize their child's sugar consumption to reduce the risk of cancer complications.

"Cut down the sugar, less sugar because we found some of the this (information), from the internet (that mentioned cancer cells like to eat sugar) also, sugar will what (do you call)... they will generate more the this la, what, the cell will what (do you call), all cancer cell will what (do you call) more to... they, they, they like to eat sugar." (Mr. AA, 58 years old)

"...sugar will cause cancer cells to multiply." (Mrs. MF, 45 years old)

Theme 2: Childcare

Need to remain strong for the child

Many caregivers believed they had to put on a facade of strength to mask their insecurities, especially in front of their children. One parent admitted that behind the strong facade, they sought help from God through prayer. Another parent expressed their concerns over the potential influence of her reactions toward her child.

"Children, to them, we act like there is nothing (abnormal), but of course, we pray for them la right." (Mrs. RH, 39 years old)

"So, I am like... we won't express sadness in front of him or what, no, of course, he will also, he... because I want to prevent him from feeling sorry for himself." (Mrs. SM, 41 years old)

Caregivers perceived that self-care was essential to maintain their health and well-being. Only then were they able to take care of others. A father highlighted the reason for the perceived importance of self-care, which is to avoid placing an additional burden onto others in the unfortunate circumstance where self-care fails.

"See, I got all the problems, so you also understand. So, I need to take care of myself also. If I don't take care of myself, if something happens to me, then the problem will be double for my wife." (Mr. AA, 58 years old)

A mother shared that she lived by the aphorism 'fake it to make it'. She believed that putting on a strong front when facing life's challenges eventually led her to be strong (in spirits) in reality.

"Like I have to be strong la, move on with life, go on with his chemo. We follow what the doctor says. So, in the long run, the strength will come la." (Mrs. SMM, 34 years old)

Self-sacrifice

The element of self-sacrifice was also present. Caregivers expressed willingness to trade their lives with their child who

had cancer. Having gone through the experience where they witnessed their child's debilities but at the same time not having the control to ease their child's pain, one mother cited her death as the solution.

"Like the tension looking at my child, feel like saying, like last time, he had blood in his urine and excretion before right, that moment, I felt it was better for me just to die." (Mrs. W, 43 years old)

A father indicated that he was willing to absorb the negative elements that accompanied the caregiving experience as he perceived himself to be the ablest to withstand it among members of the family.

"I don't want that. So, I will absorb the thing. Anything, I will absorb the stress ah. I can absorb the stress because I got nothing to do right now, so that's why I don't stress myself that much." (Mr. AA, 58 years old)

Theme 3: Treatment

Chemotherapy is heaty

Most caregivers had a strong belief that chemotherapy is heaty due to its properties. Although they did not know the exact composition of medication used in the treatment, one parent attributed heatiness to the burning sensations reported post-treatment. Heatiness, in this context, refers to the excessive amount of heat in the body of a child who has undergone chemotherapy.

"Ya, from what I see and what I hear and what I read la because in the Google also it says will be like burning sensation, but I am not sure la right." (Mr. AA, 58 years old)

"It is a liquid medication used in chemo causing it to be heaty." (Mrs. MF, 45 years old)

Chemotherapy is damaging

Chemotherapy was also believed to have negative consequences on a child's health. A parent noticed a significant emotional change in her child after undergoing treatment, while another parent compared the effects of chemotherapy to be as harmful as bleach. A similar belief was shared by a grandmother who stepped in as the primary caregiver when her daughter was pregnant, claiming that there were accumulated toxins in the body from the medications after undergoing chemotherapy that she wanted to eliminate bodily.

"There is a challenge in terms of his disturbed disturbing emotion, uncontrollable, anger maybe may be due to the side effects of chemo." (Mrs. HK, 30 years old)

"Force (him) to eat also because chemo will... if the stomach is empty, it is already sick, even a short delay also cannot stand because chemo is like Clorox." (Mrs. W, 43 years old)

"So, besides that also, she needs to do a lot of activity la for energy, to sweat, remove the toxin in the body. Chemo also has caused her to accumulate a lot of medicine in her body, so she does (exercise) to recycle, we also let her sweat it out la." (Mrs. MF, 45 years old)

Natural/home remedies are effective to facilitate treatment

Many caregivers believed that drinking plenty of fluid is a natural remedy to combat the damaging effects of

chemotherapy. Often, they made herbal tea as they believed in the benefits of a natural remedy accessible at home. One of the main benefits emphasized by the caregivers was the cooling properties they have on the child's body.

"Ah, barley ah. They also have some, to reduce some air la water according to the some of the group say barley will help to reduce any, will increase the metabolism of the body also." (Mrs. AA, 58 years old)

The grandmother recounted prior knowledge that salt has antiseptic properties. Putting this knowledge into practical use, she diluted salt with water to treat her granddaughter's ulcer, which she had noticed post-chemotherapy treatment.

"Ok, you know if your child is at home, for me la, my child has an ulcer, my granddaughter, I'll give her saltwater, on my own. I take my own alternative, I add salt into water, not too salty, a little bit of taste, for her to gargle, heal her because salt is an antiseptic, so we make our own treatment la." (Mrs. MF, 45 years old)

Theme 4: Cause of Cancer

Food choice pre-diagnosis

Although many caregivers admitted to the lack of knowledge before the leukemia diagnosis, caregivers from two separate families, in particular, perceived that their lifestyle choices before their child was diagnosed with cancer held potential significance as predisposing factors. A pair of caregivers carried a sense of guilt as they shared how they allowed the child to drink a kind of probiotic milk drink in amounts that they now perceived as excessive.

"But just a piece of advice la. With him, he got this (leukemia) because he drinks Vitagen often... Asked the doctor what the cause of heredity is. Maybe because he likes to drink Vitagen. One bundle, for sure, it's for him alone." (Mrs. FR, 38 years old, and Mr. HN, 43 years old)

Stress

Throughout the interview, a father talked about stress many times, indicating its significance to him. He shared his perspective on stress and its role in the progression of an illness. He held the belief that unmanageable stress was one of the factors contributing to his child's cancer and, as such, believed that managing stress could expedite the child's recovery process.

"If you can control the stress, you can control the, the what, to minimize the, what (do you call), to make the cure faster." (Mr. AA, 58 years old)

Theme 5: Source of Belief

Doctor

Most caregivers held firm beliefs because the doctor seemingly emphasized these practices during their hospital visits. Therefore, they viewed their doctor as the expert. Some caregivers stated that they would follow the advice of the doctor as they only trusted them to provide valid and reliable information.

"Do not eat the wrong things la, scared that his blood will get infected, the doctor said so. I just follow the doctor's advice la." (Mrs. W, 43 years old)

"From my experience la, this cancer thing need to listen to the doctor's advice. When other people say things also, cannot listen

to them, that's it la." (Mr. AL, 41 years old and Mrs. SK, 38 years old)

Online platforms

Besides obtaining information from the doctor, some caregivers' beliefs stemmed from information from online platforms. This included taking the initiative to do their research online and connecting with support groups through chat applications. An important point to note is that medical experts were absent from these support/chat groups, and the empirical evidence of the articles read by the caregivers was not known.

"Yes la, sources of information from the CAKNE also help la. CAKNE the group ah, the WhatsApp group. Some members, sometimes they having problems, they go to this group and explain what to do and what... so, some experience come from there la also so all the mothers and parents also get involved in the group and say what this, this, this la, like that." (Mr. AA, 58 years old)

"I search via Google..." (Mrs. MF, 45 years old)

Personal experience/observation

It seemed that first-hand experience and observation had a lasting impact on the caregivers' belief systems. A parent deduced that chemotherapy was heaty after witnessing other children's reaction to removing their clothes and fanning themselves post-treatment. Another caregiver shared that drinking plenty of water was emphasized since she was young, and this piece of advice had been passed down to the following generations, becoming the standard practice in her family. For this caregiver, personal experiences had a seemingly strong impact on her, in which she tended to generalize to other individuals and catastrophize its implications for cancer patients.

"(After chemo) Ah, take off the shirt ah and the parents will buy an extra fan, the small fan to this, you know. Sometimes, the aircond is already cold, but they still need the circulation of the this, you know, something to cool down or maybe yala. Ah, yala, I don't know." (Mr. AA, 58 years old)

"For drinking lots of water, I was educated since I was young... That was instilled since young la. Like my mother will educate me from young, I educate my daughter, my daughter then educates her daughter." (Mrs. MF, 45 years old)

"Because when I consume (food cooked with used oil), I become allergic, when I eat, the breathing at my chest. I can feel like pressure. So, the used oil has become like cholesterol because it has been fried many times. So, when I can feel that, what else for cancer patients. It will be worse if they are the ones who consume." (Mrs. MF, 45 years old)

Food labels

For one of the caregivers, who was cautious and interested in the nutritional value of food, food labels became a source of her belief. The key points that were important to her assessment of whether or not a food or beverage was safe to consume were natural or organic ingredients and listed as safe to consume by infants. Therefore, she perceived that food or beverage safe for infants would be safe for everyone.

"I personally take supplements too, but the supplements that I take, I will look at the ingredients. And then, what is its function. I look at this; it's an organic supplement. Okay, if organic, I see plants, 100% natural, no chemical ingredients, ah, I will take. Now,

I allow (the patient) to take this supplement too.” (Mrs. MF, 45 years old)

“Because its (supplement) function is for blur vision, kidney stones, blood cleansing, intestinal cleansing, hemorrhoids. And then, cholesterol, allergy, and one more, which was strange to me, jaundice. So, from there, jaundice, that means, this thing is safe because jaundice, that means newborn babies. Ah, so when it mentioned jaundice, I read in the pamphlet, I went, wah, I see a lot, so I bought.” (Mrs. MF, 45 years old)

Discussion

A childhood cancer diagnosis carries lasting repercussions for the caregiver. Throughout illness, caregivers develop beliefs that impact their behavior towards caregiving practices, thus directly affecting treatment adherence and outcomes. Findings from this study provided insight into the lived experience of caregiver beliefs and the sources of their belief systems based on a multicultural context.

The first theme on dietary intake reflected caregivers' belief that diet was vital to their child's recovery. As opposed to the Westerns, caregivers in Asia place a higher emphasis on a diet (Bell et al., 2009). Particularly in Malaysia, food insecurity is still prevalent among Malaysian households, thus explaining the focus on meeting the necessary dietary requirements (Sulaiman et al., 2021). Globally, however, dietary habit was reported to be associated with ALL children's survival, regardless of one's country of origin (Barr et al., 2016). Therefore, an error in choosing or providing children with the wrong choices of food may complicate the progression of cancer by contagion or infection. The constant sense of worry, even after treatment had ended, seemed to be common as similar concerns were expressed by parents who were troubled by the risk of infection as they transitioned to resuming daily activities (Earle et al., 2007). This sense of uncertainty resembling state anxiety was also reported by other caregivers (Wijnberg Williams et al., 2006). Longstanding anxiety, where excessive worry that exists across the different illness phases is concerning as if left unaddressed, may turn into a clinical disorder. Particularly in this local study, anxiety is magnified in the area of dietary intake.

The second theme on childcare provided insight into caregivers' belief for the need to put on a facade of strength throughout treatment and the sacrificial element in caregiving. Van Schoors et al. (2018) discussed parents' struggle for normality which was a possible mechanism for balance and hope. This is similar to findings in this study where one parent believed that putting on a strong front will eventually give her strength, while other caregivers shared that they avoided showing negative emotions, especially in front of the child, to prevent him from feeling sorry for himself. These illustrate caregivers' struggle to maintain normality and hope. This is also in line with mothers who felt the need to be strong for others in the presence of their children out of the fear of putting them in distress (McGrath, 2002). These beliefs may be associated with the concept of parents as authority figures and self-sacrifice. A recent survey has shown that the element of authority is present in Malaysian parenting styles, with that being more intense among fathers as compared to mothers

(Woon & Chin, 2018). Self-sacrifice also seems to be particularly prevalent among Malaysian caregivers, and similar to the findings in this study, hiding worries from their children was considered a part of self-sacrifice (Akhmal et al., 2018). This can be viewed through the lens of a collectivist culture where personal needs are abandoned for the benefit of other members in the same group (Grusec et al., 1997).

The third theme on treatment reflected caregiver beliefs that chemotherapy consisted of harmful substances and had negative effects on the child's emotions, toxicity to the body, and 'heatiness'. Heatiness originates from the Traditional Chinese Medicine (TCM) concept of 'yin' and 'yang', which translates to hot and cold. Generally, this term refers to the state of one's physical well-being, and an imbalance between these two states (hot and cold) indicates illness (Ho et al., 2019). Findings from this study contrasted with other studies, where parents viewed their children's personality change as a consequence of development instead of treatment (Earle et al., 2007). Most of them viewed chemotherapy positively, and only a minority (6%) opted for natural substances to replace conventional treatment (Mostert et al., 2008). For instance, some caregivers in this study talked about the benefits of herbal tea, especially the cooling properties, to ward off the heatiness from chemotherapy. This finding was typical in the local context where complementary and alternative medicine (CAM), such as the consumption of supplements and Chinese traditional medicine, was used to complement conventional treatment (Hamidah et al., 2009).

Although caregivers believed that alternative medicine might aid cancer recovery, none of them in this study believed that it could be used independently without conventional treatment. Caregivers in this study often opted for alternative natural/home remedies only to treat their child's minor illnesses, such as salt to treat ulcers. This is in accordance with parents of ALL, who derived practices from their personal experiences to manage their child's pain and preferred the use of strategies that did not involve medication (Bettle et al., 2018). Caregivers' reservations towards Western medicine may be associated with their belief in the side effects. Despite this, however, caregivers were still able to find a balance between modern and traditional treatment, with the latter being employed only when the illness is acute and perceived to be mild. Compared to Western medicine, the regulation of traditional Chinese medicine (TCM) in the Malaysian healthcare system is less than 50 years old, thus possibly affecting its dominance in the country (Wong et al., 2019).

Nevertheless, it is important for healthcare providers to offer caregivers the opportunity to share their views on treatment as caregivers' perception of treatment effectiveness may affect their level of adherence to the recommended strategy. According to the Health Belief Model, one way to increase treatment adherence is to ensure that the perceived benefits outweigh the perceived barriers (Hochbaum et al., 1952). Therefore, caregivers and healthcare providers must have a collaborative relationship in weighing the costs and benefits of treatment strategies and alternatives.

The fourth theme on the causes of cancer reflected caregiver beliefs that their choice of food and beverage and stressors were possible contributing factors to leukemia. Families tended to attribute the causes of cancer to external environmental factors and the quality of care provided to the

child in their early years (Kohlsdorf & Costa Junior, 2012). These feelings of self-blame and guilt are common as mothers in other Asian countries such as Taiwan and cities such as Amman reported the same (Atout et al., 2021; Chen et al., 2020). These beliefs must be viewed with caution, however. Guilt and self-blame may impact the ability of these caregivers to manage their children, as they engage in constant rumination on their past choices that are irreversible. While two families shared their views on possible causes of cancer, other caregivers in this study were uncertain about this. It is not uncommon as parents (59%) in other studies were also unsure about the causes of leukemia (Mostert et al., 2008). This situation calls for educational programs to increase health literacy among caregivers, especially on the nature and causes of cancer. Caregiver training programs conducted by a team of multidisciplinary professionals were found to have improved caregivers' ability to seek related health information and reduced caregiver burden, thus improving their ability to care for their child and quality of life (Cianfrocca et al., 2018).

The fifth theme highlighted that doctors, online platforms, personal encounters, and food labels/information were the sources of information that either formed or reinforced caregivers' existing beliefs. Most caregivers shared that they relied heavily on information provided by the doctors and followed their advice, while a few others actively went on online platforms to obtain more cancer-related information. Caregivers additionally joined online support groups to connect with other caregivers of children with ALL. This is similar globally, where it was found that parents' motivation to learn new information helped them care for their children better and that they relied on healthcare professionals for cancer-related information, especially in the initial stages of diagnosis (Bettle et al., 2018; Mostert et al., 2008). In addition, parents find it necessary to have a safe space to share their emotions with other parents who have gone through the same experience (Hocking et al., 2014). Social support and being accepted as a member of a group with like-minded individuals are especially relevant in a collectivist culture.

One caregiver mentioned that she shared her supplement with her granddaughter (the patient) due to its supposed benefits and natural properties. This may be driven by the cultural belief that medicinal herbs are natural products that are non-harmful and have no side effects (Ariff & Beng, 2006). As the sources of information shared by the caregivers were wide and varied, it is essential to ensure that the information obtained is valid to avoid cancer complications or detrimental effects on one's health. The consideration of cultural factors is also crucial during the dissemination of information due to their level of accessibility. For example, ingredients used to prepare a dish may be more accessible to a selected ethnic group as it is restricted by another ethnic group to consume such ingredients. Therefore, it is necessary for hospitals to provide adequate guidance and referrals for patients and their families to discuss and consume the right materials and information. Among them are parental support groups, supportive cancer care by a team of multidisciplinary professionals, and educational leaflets. Training programs can also be conducted with healthcare professionals on effective communication with patients to create a safe space to share their thoughts constructively.

Limitations

There were a few limitations in this study. Firstly, the distribution of ethnicity, religion, and gender among the respondents were not representative of the major ethnicity in the country; thus, possibly affecting the findings of this study which leaned towards the Malay, Muslim female category. Most of the primary caregivers' respondents appeared to be mothers (and one grandmother). The participation of fathers is still lacking in research (Kazak et al., 2004). While most interviews were conducted with caregivers during their children's hospital follow-up visitation, others were conducted through the phone when caregivers indicated their preference. In such circumstances, there were barriers to a more meaningful interpretation of their statement as their facial expressions could not be viewed through the phone. It is also important to note that this is a single-center study. Lastly, the interview was conducted in two languages. Therefore, the Malay to English translation of the transcripts may potentially cause some inaccuracy compared to the original meaning of words. Thus, painting a less accurate picture of the respondents' intended message.

Conclusion

Our findings offer insight into caregivers of a specific cancer subgroup - ALL's globally shared beliefs on the importance of dietary habits in cancer treatment and dietary concerns associated with the prevalence of food insecurity in Malaysia. Rooted in Malaysia's collectivist culture, caregivers emphasize the need to be strong, self-sacrifice, and shared need for social support. Their divided view on chemotherapy and their preference for natural remedies are associated with traditional (TCM) beliefs on achieving a natural balance in the body. Subsequently, the dissemination of accurate information that reinforces rational beliefs and corrects irrational beliefs should be emphasized as caregiver practices resulting from these beliefs may unwittingly impact treatment outcomes. Generally, nurses play an essential role between healthcare professionals and patients and/or their caregivers as they spend most of their time working closely with them, such as during treatment procedures.

Given that the number of allied health professionals (clinical psychologists) in Malaysia is lacking, nurses can be empowered to provide supportive care, including psychological support, early detection of psychological distress among patients and/or their caregivers, and the exploration of caregiver beliefs that may impact treatment outcomes. Findings from this study could be used to develop a psychosocial module for caregivers. Therefore, these findings are important to inform decisions associated with the module, which will be vital as a potential guideline to train nurses in its delivery. Furthermore, it helps secure the sustainability of psychosocial interventions for caregivers as there is a greater preference for care to be provided by doctors or nurses, as compared to mental health or allied health professionals, due to the possible fear of stigmatization.

Declaration of Conflicting Interest

The authors declare that there is no known conflict of interest.

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Authors' Contributions

ASSC, AM, and CMHC conceived and designed the study. HA facilitated the participants' recruitment while AC performed the qualitative study with guidance from AM, CMHC, AH, IHR, and LA. ASSC analyzed the results with close guidance and cross-checking with CHMC as an expert in psychosocial oncology involving qualitative methods, MA as an expert in health psychology, HA as an expert in the field of pediatric oncology, and RIH as an expert in the field of radiology. ASSC wrote the manuscript draft, while all authors discussed the results and were responsible for the critical revision of the manuscript. All authors have read and approved the final manuscript.

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Data Availability

Data sharing (of the interview transcript) is not applicable to this article. However, the themes generated from the qualitative interview are included in this article.

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