

# OUR CHILD IS DYING: EXPLORING THE EXPERIENCES, CHALLENGES AND COPING MECHANISMS OF MALAYSIAN PARENTS AS CAREGIVERS OF A CHILD WITH CANCER

Hasniza Ibrahim\*, Marini Razak, Azlina Aman, & Ismail Sheikh Ahmad

\*First author

Kuliyah of Education

International Islamic University Malaysia

Gombak, Malaysia

(hasniezaibrahim@gmail.com; marinirazak18@gmail.com;  
azlinaaman.iium@gmail.com; drismail@iium.edu.my)

DOI: <https://doi.org/10.22452/jati.vol24no2.5>

## Abstract

Parents as caregivers to paediatric cancer patients face various challenges. This paper highlights the characteristics, caregiving tasks, resources, and other role demands/stressors experienced by a pair of parents as primary family caregivers of a child with cancer in the Malaysian setting. Besides, coping strategies are also put forward as a significant element in understanding the functions of a parent as a caregiver. Hence, this study aims to explore the in-depth experiences of caregivers and investigate the challenges as well as the coping strategies adopted by them, particularly as Muslims. Eight (8) main themes emerged from the findings: (i) chronology; (ii) caregiver roles; (iii) routine changes; (iv) making decisions; (v) financial; (vi) letting go; (vii) external support; and (viii) internal support. This study is unique because the patient was an only child, and he managed to score excellent grades in all subjects in the Malaysian Primary School Achievement Test (UPSR) despite not attending school for almost one year due to cancer treatments.

*Keywords:* cancer caregiver, Wilms' Tumour, Muslim caregiver, exploratory qualitative research

## Background

Cancer is one of the leading and common causes of death in Malaysia. Approximately 37,400 people were diagnosed with cancer every year (Ferlay et

al., 2012), and a total of 103,507 new cancer cases were diagnosed during the period between 2007 and 2011 (National Cancer Institute [NCI], 2016). The Ministry of Health (2018) reported that during that same period, the most common cancers in children under the age of 14 were: (i) leukaemia (46.4%); (ii) brain and nervous system (14.8%); and (iii) lymphoma (10.1%). Meanwhile, Hamilton and Shamberger (2012) claimed that Wilms' Tumour (WT) is the most common renal cancer that occurs in childhood. In the United States, the renal tumour is the fifth most common cancer in children, and it is estimated that 7.1 per million children are affected (Kalapurakal & Dome, 2015). Wilms' Tumour (nephroblastoma) is the most common primary solid malignant tumour of the kidney in childhood. WT is named after Max Wilms, the first to identify the mixed cellular elements of the neoplasm (Kalapurakal & Dome, 2015). Even though the cause of WT remains unknown, the survival of children with WT gradually increased from less than 10% to about 50% by the 1940s and 1950s (Kalapurakal & Dome, 2015). In the early 21<sup>st</sup> century, the advent of effective chemotherapy and the systematic development of multidisciplinary management for Wilms' Tumour increased the survival rate (Kalapurakal & Dome, 2015).

Receiving news of cancer diagnosis and arranging for the needed subsequent care affected both the patient and the patient's family members. The diagnosis of childhood cancer initiates a difficult and painful experience for families who are confronted not only with overwhelming information and difficult decisions inherent to cancer treatment but also their feelings and insecurities (Bally et al., 2014). Caregiving is typically something that is neither anticipated nor chosen. In confronting cancer diagnosis and treatment, family members feel obligated to provide care and are committed to providing limitless care (Coolbrandt et al., 2015; Senden et al., 2015). However, usually, family caregivers take on this responsibility with little or no training and with limited resources (Ferrell, Hanson, & Grant, 2013). Family caregivers experience a considerable amount of distress to provide care for cancer patients. Caregiving burden is defined as the distress felt by the caregivers as a result of providing care (Given, Given, & Kozachik, 2001).

Living with a chronic disease such as cancer can be taxing. Peculiarities, demands, and challenges of aggressive treatments and iterative hospitalisations can lead to a series of manifestations of anxiety, fear, guilt, anger, and sufferings that are common to all family members (Belgacem et al., 2013; West, Bell, Woodgate, & Moules, 2015). The impact of the disease entails increased care needs, changes in social interactions and lifestyle, and reassessment of the family functioning to adapt to the demands of treatments (Bally et al., 2014; West et al.,

2015). Moreover, financial problems and emotional instability resulting from the presence of cancer can lead to estranged family relationships, including the parents' marital relationship. Hence, such effects of dealing with cancer can lead to distress, depression, and a decline in quality of life (Belgacem et al., 2013)

Despite the extensive acknowledgement of the crucial role played by the family as informal caregivers of cancer patients, there are still limited available resources regarding the former's tasks in attending to the patients. It includes their needs, their challenges, and other stressors they encounter, and their coping strategies (Harwood et al., 2000). The experiences of cancer caregivers might prompt the use of particular coping strategies across more general domains of function as well as in specific stressful situations. This notion is consistent with Folkman and Lazarus (1980), who proposed The Cognitive Transactional Model of Stress and Coping. This model of stress consists of two types of appraisals: Primary Appraisal and Secondary Appraisal. According to the model, the individual creates an impression of their ability to control or cope with the stressor. Along this line, coping strategies of cancer caregivers give different perspectives depending on the background, concurrent symptoms, and support they receive. Extensive studies have evidenced a range of potential coping strategies engaged by cancer caregivers, such as emotion-oriented coping, problem-oriented coping styles, self-blaming, self-isolating and distancing coping, and avoidant coping (Harris et al., 2016). Arruda-Colli, Perina, and Santos (2015) identified six (6) coping strategies adopted by family caregivers: (i) faith; (ii) family support; (iii) social support; (iv) perception of child's coping; (v) development of sense of power; and (vi) trust in the hospital institution.

Providing information that is proven to be a strategy is considered helpful by caregivers. Fraley (1986) acknowledged that parents appreciated more explanations about their child's condition, treatments, and procedures. They also appreciated being offered information regarding available medical care services and sources of funding. Glenn (2015) reported that parents found health care providers who displayed an interest in their child and the child's illness to be positive. Additionally, spirituality and religiousness are two other coping strategies important to parents with children who have cancer. Spirituality and religiousness are distinguishable constructs, albeit overlapping (Zinnbauer, Pargament, & Scott, 1999). Spirituality may be defined as a combination of religious and existential (non-religious, related to meaning and purpose in life) well-being (Laubmeier, Zakowski, & Bair, 2004). In contrast, religiousness is a social phenomenon. Religions are defined by the borders of institutional belonging, belief systems, traditions, and practical commitments (Laubmeier et al., 2004).

Most studies have focused on female caregivers and reported that female caregivers experienced higher levels of caregiving stress than their male counterparts. It is a common trait in many cultures where women are expected to be family caregivers (Kim, Baker, & Spillers, 2007). While there has been a global increase in research on cancer caregivers over the past decade, in-depth research in Malaysia focusing on both male and female Muslim caregivers is still lacking. This study is unique not only because it contributes to the paucity as mentioned above, but also because the cancer patient is an only child who was conceived after a long wait. Furthermore, despite not attending school for almost a year during his final primary school year (grade six) due to the cancer treatments, the child was able to achieve top scores in all subjects in the Malaysian Primary School Achievement Test, *Ujian Pencapaian Sekolah Rendah* (UPSR). This uniqueness motivated the researcher to study this family's experiences and challenges in combating cancer successfully. Therefore, this study aims to explore the informal caregivers' experiences, challenges, and coping mechanisms while taking care of their cancer child. Hence, the primary research objectives are: (1) to explore the experiences of Muslim caregivers in dealing with a cancer child; (2) to understand the challenges Muslim caregivers face in dealing with a cancer child; and (3) to study how the Muslim caregivers of a cancer child cope with the challenges.

## Methodology

As this study focuses on the real-life experiences of Muslim caregivers, the researcher has chosen the exploratory qualitative research design in order to provide a comprehensive insight into the phenomenon. The family is Malaysian and Malay Muslims. They were living in Mantin, Negeri Sembilan when the disease was first diagnosed, and the chemotherapy treatments (CT) and radiotherapy treatments (RT) began. When the patient had completed his primary school education, he was accepted into a secondary school in Selangor. Therefore, they moved to Salak Tinggi, Selangor after the CT sessions were almost completed. The informants of this study are the patient's father and mother. These informants were intentionally selected as they are the caregivers who have specific characteristics as required by the study. As caregivers to a child with cancer, parents have various perceptions based on their beliefs and background, in line with the difficulties and challenges they encounter. A father and a mother play different roles in taking care of the sick child. Therefore, the researchers were interested in studying and exploring both parents' respective experiences in dealing with a cancer child. Concurrently, the researchers also wanted to study how they managed to cope with the situation. In order to gather

rich data, the researchers employed the language that the informants are most comfortable using in the interview. This would ensure the informants are able to express their thoughts freely.

The main instrument employed in this study was an interview. To ensure the data elicited from the informants address the research questions, the researchers used the standardised open-ended interview method (Turner, 2010) where the interview questions were structured such that they were carefully worded to elicit open-ended responses from the informants. The data gathered from the interview were supplemented with research field notes, including the patient's treatment logbook, as a triangulation of data. Pre-prepared interview protocols ensured the interview sessions were carried out ethically, such as when requesting for the informants' consent and explaining to them the purpose and the objectives of the interview. The informants agreed to share all the information requested during the interview. Therefore, no issues arose concerning the confidentiality of the informants. The interviews were recorded digitally using a voice recorder and transcribed into the transcription template. The verbatim transcripts of the interview in the Kelantan dialect were translated into English for data analysis purposes. Themes were generated and analysed to answer the research questions.

To ensure the data collected was sound and reliable, the researcher adopted three criteria proposed by Guba and Lincoln (1994). First, a member check is where the caregiver-informants were asked to read and discuss the interview transcripts to check the accuracy of the data gathered from them. Second, triangulation was conducted to ensure congruence of the data collected; besides the interview, the researcher also made field notes and references to the patient's logbook. Third, to apply prolonged engagement, the researchers established a good relationship with the informants, to gain adequate understanding and trust to enable the latter to be more open in their sharing. Thus, the researcher was able to witness their experiences from the beginning until the end of the patient's life.

Validity and reliability were taken seriously to ensure the credibility of this study. Researchers play an important role in gathering qualitative data as the researchers are the factors that validate the data (Bahrami, Soleimani, Yaghoobzadeh, & Ranjbar, 2016). Ethical considerations were not neglected in this study. The ethical components taken into considerations are: (i) the role of the researcher; and (ii) the informants' informed consent. In this study, a pilot test was conducted in the form of an interview session with another chronic disease caregiver in Selangor. Inter-rater reliability checks were conducted to determine the reliability of the interview questions and the coding scheme.

According to Keyton et al. (2004), inter-rater reliability is done to ensure the data are collected consistently throughout the study, while Krippendorff (1984) mentioned that a good measure of inter-rater reliability would create a sense of confidence that the instrument is able to collect the intended information. Thus, inter-rater reliability checks were conducted whereby the interview questions and the coded transcriptions of the interviews were sent to two reliable raters. The Percentage of Agreement is 95.1%.

## **Findings**

As part of the triangulation and with the consent of the caregivers, the researchers utilised the patient's treatment logbook to gather additional data, particularly those related to the specific dates. Because the events happened five years ago, obtaining the exact dates is important in ensuring the validity of the data. Table 1 shows the clinical characteristics of the patient.

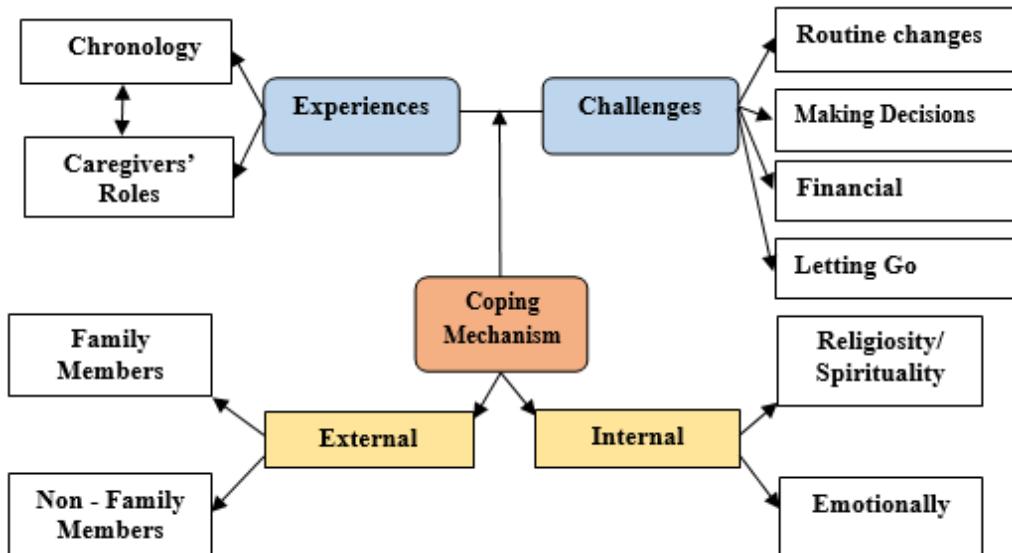
**Table 1: Clinical Characteristics of the Child Selected for the Study**

<b>Age (When Diagnosed)</b>	11 years 2 months
<b>Diagnosis</b>	Wilms' Tumour (cancer)
<b>First Medical Appointment</b>	January 2012
<b>USG Abdomen</b>	13 February 2012
<b>Operation Date</b>	21 February 2012
<b>Treatment in Private Clinic/Hospital</b>	Normal check-up Scan Water retention treated
<b>Treatment in Hospital Kuala Lumpur (HKL)</b>	Scan Surgery Lab test Chemotherapy Radiotherapy Treatment for ulcer Referred to neurologist Water retention treated
<b>Other Treatment</b>	Traditional/alternative treatment
<b>Chemotherapy Treatment Cycle</b>	1 year 3 months (7 March 2012 – 26 June 2013)
<b>Radiotherapy Treatments</b>	9 May 2012 – 28 May 2012
<b>Neurologist</b>	30 May 2012 – 8 August 2012
<b>Recurrence</b>	13 November 2013
<b>Date of Death</b>	29 May 2014, 10 pm

(Source: Patients' Treatments Logbook)

After transcribing and generating themes according to the RQ and IQ, the researchers identified eight (8) main themes: (i) chronology; (ii) caregivers' roles; (iii) routine changes; (iv) making decisions; (v) financial; (vi) letting go; (vii) internal support; and (viii) external support. The themes and sub-themes are summarized in Figure 1 below.

**Figure 1: The Expansion of Emerging Themes**



## **Experiences**

From the findings, two themes emerged from Experiences: Chronology and Caregivers' Roles. Chronology is important as it provides the timeline of the flow of the incidents. The caregivers' roles, as played out at each stage of the chronology, were also explored. Four (4) categories or stages of chronology were identified: pre-diagnosis, post-diagnosis, recurrence, and deceased. Meanwhile, the caregivers' roles included (i) tender loving care (TLC); (ii) making decisions; (iii) providing treatment; (iv) supporting emotionally/spiritually; (v) assisting patient's study; and (vi) providing financial support.

## **Chronology**

### ***Pre-Diagnosis***

Informant 2, the father of the cancer child, said that he realised something was amiss with his son when one night, he noticed that his son stayed awake until

very late. He said, "One night, he went to sleep, but when I saw him in his room around 11 pm, he did not sleep, he cannot sleep". He then suspected something was not right because it prolonged for over a few weeks. Subsequently, he brought his son to a private clinic at Nilai. The specialist scanned his son and found something abnormal in the stomach. On the same day, the specialist wrote a reference letter and asked the father to send his son to Hospital Kuala Lumpur (HKL). In HKL, the son was directly sent to the paediatric operation ward and referred to a specialist. According to Informant 1, this event occurred approximately two months after the son celebrated his eleventh birthday. She said, "February 2012 was the beginning that we know something was not right with him". After it was confirmed that there was a tumour on the left kidney, the son had to undergo surgery immediately because the tumour has already large. The son was hospitalised after the surgery where concomitantly the hospital conducted tests on the tumour cells. The test results confirmed that it was Stage 4 cancer. The tumour ruptured during the surgery and spread to the lungs. Soon after, the son was referred to a cancer specialist.

### ***Post-Diagnosis***

After it was confirmed that it was a Stage 4 cancer, the specialist met with both father and mother to discuss the subsequent treatments. Informant 2 mentioned that "Yes, we met the cancer specialist, he said that there are few treatments which are chemotherapy (CT) and radiotherapy (RT)." According to Informant 1, the CT started in March 2012. This cycle of CT ended in June 2013. She explained, "The schedule for CT treatments took approximately more than one year. In the beginning, the treatment was once per week. The frequency of the treatments varies, and the drugs used for the treatment also varies." Informant 2 said that they decided to treat only the left kidney because he had thought that his son could still survive with only one kidney if he survived cancer. "But, during the CT treatments, he also went through another treatment," said the mother. The father explained, "He also needed radiotherapy (RT) treatment. This treatment is just a short-term treatment conducted during the cycle of chemotherapy treatment (CT). It was a daily routine for approximately 10 days."

The patient was in Standard Six (Primary Year 6) when he underwent the cycle of chemotherapy treatments. Informant 1 said that during the treatment, her son was unable to attend school for almost one year. She said, "He was at standard six, he only attended the school in January and missed almost all of the classes after that". However, her son attended school for two or three days and several seminars in August because he missed his classmates so much. Unfortunately, he could not sit for the UPSR trial examination because of the

problem with his fingers that caused him unable to write. To his parents' surprise, approximately two months later, he was able to sit for the UPSR examination, and according to Informant 1, he scored straight A in the examination.

### ***Recurrence***

In early 2013, the patient was getting better and able to attend school for almost one year. He was in Form One (Secondary Year 1) when the chemotherapy treatment cycle comes to an end. However, towards the end of 2013, when the doctor scanned and rechecked, the disease had reappeared at the same spot. Informant 2 explained, "It attacked again! The specialist offered the treatment, but my wife and I were reluctant. We refused because we had witnessed all the consequences during the first cycle of chemotherapy treatment. And when we asked Aqil, he also refused and reluctant to repeat the same experiences". With tears in his eyes, Informant 2 said, "After some discussion, finally the three of us agreed not to proceed another cycle of chemotherapy treatment in HKL and decided to find alternative medicine for our child. However, we are still allowed to refer to HKL for certain circumstances." He also added, "But this time, the disease was too aggressive. We can see the effect very quickly and was too obvious".

### ***Deceased***

After the second attack and suffering for a few months, the patient was admitted to HKL once again. He was admitted approximately for two weeks, and his condition worsened day by day. The parents continued to hope for the best for their son. Informant 2 remembered the event in great detail and shared his experiences with tears flowing down his cheeks, "I used [sic] the train and daily shuttle from the hospital to my workplace to visit him. However, on the day he passed away, it was Thursday night, two days before that, my son did not allow me going to work. I did not go to work on Wednesday and Thursday; I stayed with him. I can see, and I can feel that he was very ill, and his time to leave was approaching. I knew, and the doctor also said that he has no chance anymore, but, as a parent, no matter what, I still hope that he can survive...".

Unfortunately, the dreaded day came, as Informant 1 shared, "Approximately at 10 pm, 29 May 2014, Friday night, 1<sup>st</sup> Syaaban" the patient passed away. Informant 1 shared her experiences of the moments as follows:

He said syahadah after me and became very weak again. His father was not in the room; I was waiting for him too. I waited while leading my son

to say syahadah. Approximately five minutes later, when he saw his father opened the door, he called 'Abah!' and immediately hugged his father. He hugged his father very tight for a while. Then, he said 'Allahuakbar' and passed away.

## **Caregivers' Role**

### ***Providing Treatment***

The caregivers played crucial roles in overcoming the challenges. The findings of this study showed that both parents complement each other in providing care and treatments to their cancer-ridden son. Both informants mentioned this information. For instance, Informant 2 admitted, "For example, when I was working, and suddenly Aqil had a high fever at home, my wife called and informed me. I rushed home immediately." Since the father was the sole breadwinner and the mother was a fulltime housewife, the mother had more time to spend with their son. While the father was at work, the mother must always be alert and check the son's condition, especially his body temperature. Informant 1 shared,

In May or April 2013, he had a high fever. But before Fajr prayer, his body temperature increased to 41°C. Ya Allah. I placed a wet towel on his body with a hope [sic] it can reduce the heat. And I insert a suppository in his anus too. I was alone and very scared. I need to do it fast. He was trembling.

She said if the body temperature further rising, they need to send their son to the hospital immediately. Hence, the mother called her husband to come home and bring their son to the clinic. Informant 2 said, "I bought a thermometer to monitor his temperature. If I found that the temperature is almost 38°C, I will immediately send him to HKL." In this study, the mother did not know how to drive a car. Therefore, the father must do all the driving in sending their son to the clinic or the hospital for treatments at all times. From the findings, the researcher found that the cancer child received the treatments from Hospital Kuala Lumpur until he completed one cycle of chemotherapy treatment. However, after the second cancer invasion, the parents and the patient refused another cycle of chemotherapy treatment. Thus, the father shouldered the responsibility to provide an alternative treatment for the child as he said, "We decided not to proceed the second treatment and try my best to buy alternative medicine, as long as I can afford it, I will buy..." Meanwhile, the mother assisted the son to consume the medicine as per schedule. She explained, "I am in charge

of giving the traditional treatment. For example, I assisted him to consume traditional medicine."

### ***Making Decisions***

Another shared role by both father and mother found from the results is the decision-making, as mentioned by Informant 2, "... then, he was referred to a cancer specialist. The specialist called my wife and me to discuss for next treatments..." The researcher also discovered that the father was the final decision maker as he said, "... the doctor said that my son still can live normally with only one kidney, so I agreed to the surgery..." However, usually before making any decision, he always discusses with his wife. The wife admitted by saying, "We discussed before the surgery and agreed to proceed."

### ***Tender Loving Care***

According to Kendrick and Robinson (2002), the term 'tender loving care' (TLC) has traditionally been used in the West as a defining term that characterises nursing and exists dynamically between the carer and the cared-for. Through this study, the researcher found that TLC was firmly rooted in both caregivers. For instance, Informant 1 as a mother stayed with her son almost all the time and accompanied him everywhere he goes. She shared her experience by saying, "I accompany him repeatedly to go to the hospital for treatments. Sometimes once a week or once in two weeks. Occasionally, just after returned home from the treatment, we then immediately rushed back to the hospital because he had a high fever."

Even though Informant 2 was working when his son was diagnosed with cancer, it was not an excuse for him to not spend time with his son. He always tried his best and sacrificed his time and energy to visit his son in the hospital when the latter was hospitalised. For example, during the radiotherapy treatment, he commuted from his house to the hospital and workplace every day. He said, "The radiotherapy treatment occurred every day for 10 days. The treatment is in the morning, every day. So, I visited him every day for 10 days, and after that, I went to work ... For two weeks, I changed my shift and duty roster from morning to afternoon shift. I worked from 3 pm until 12 am."

When the father was with his son, he would spend his time wisely. For instance, if the son felt uncomfortable, he would massage his son. Similarly, the mother also did not only accompany him but even while her son was asleep, she continued to be cautious and remained alert to her son's condition. One of the significant effects of cancer and its treatments reported by both informants was that their son had lost his appetite. The patient developed an ulcer in his mouth

and often vomited. His weight reduced drastically. As a mother, Informant 1 was concerned about this. To help her son cope with it, she would cook any food that her son wished to eat and able to eat.

### ***Supporting Emotionally/Spiritually***

According to Deshields et al. (2012), helping cancer patients dealing with their feelings about cancer and providing emotional support to cancer patients are considered difficult psychological tasks. Similarly, in this study, even though the findings from the interviews indicated that both father and mother played their roles in providing emotional and spiritual support, it was not an easy task. Informant 2 understood that as a parent, he needed to be strong. He believed that if he was weak, his son would be weaker. He said "... I have to respond positively to motivate him. If I show weakness, he will be weaker ..."

Similarly, Informant 1 also said that she always said good and positive words to her son to motivate him. "Yes, I gave him motivation. I said good words in front of him even though deep inside me I felt sad. I only cried alone in the washroom." Besides her son, she also became the strength to her partner and supported her husband emotionally as she said, "I think, I [sic] am the one who encouraged my husband and gave him strengths."

Not many researchers highlight the spiritual aspect. However, this study found that providing spiritual support is significant. In terms of spirituality, both Informants 1 and 2 said that they always prayed for their son. For example, Informant 2 shared that when he could not bear to see his son suffering, he would pray, "At the final stage, he was so sick, and it was unbearable for me to see him suffered. I was thinking; it is enough. I prayed and asked from Allah, 'If he cannot live any longer, if his life just until here, God, please take him immediately, I can't hold it anymore'". Furthermore, Informant 1 also said many times during the interview that she always read and recited the Quran to her son as she claimed that her son loved listening to her recitation as she said, "He always said he is fine. But, he always requested me to recite the Quran for him."

### ***Financial Support***

The financial burden could be due to paying high medical expenses and losing income and savings (Deshields et al., 2012; Song et al., 2011). In this study, Informant 2, as the head of the family and the sole breadwinner, shouldering all the house expenses, including all medical expenses incurred. Informant 1, as a housewife, did not contribute financially to this family. However, as a Malaysian, the patient who was a primary school student, entitled to medical privileges; the Malaysian Government fully funded the treatments in HKL. Informant 2 said

that he still managed to afford the expenses at the earlier stage because they received medical treatment sponsorship from the government by using the Guarantee Letter obtained from the school. However, the cost of the treatment increased when they stopped going for the treatment at HKL and decided to seek treatment on their own. Hence, other than his monthly salary, the father also sought some other forms of financial help from his employer as he said, “ ... at that time, I needed extra money. Therefore, I met my employer and explained to them our needs during the treatments. Then, they gave me money to help us pay the treatment cost ... ”

### ***Guidance for UPSR Examination***

The patient was in Standard Six when he was diagnosed with Stage 4 cancer. In Malaysia, all Standard Six students are required to sit for a compulsory Malaysian Primary School Achievement Test or *Ujian Pencapaian Sekolah Rendah* (UPSR). According to the parents, the patient only attended school in January and was absent for almost the whole year because of cancer. Nevertheless, even though the son did not attend school for almost a year, he managed to score all A in the UPSR examination. The father played a vital role in assisting his son in his studies, which contributed to the latter's success in the examination. Informant 2 said that he did not push his son very hard for the examination as he understood his son's medical condition. He expressed his role by saying, “I told him to study and try to answer examination questions by watching a television programme in Astro Channel.” He added, “He did not go to school. I understand his condition did not allow him to attend school, so, I did not push him too hard.”

### **Challenges**

Even though previous researchers found that caregivers are burdened in many aspects including physical, psychological, social, and financial (Rha, Park, Song, Lee, & Lee, 2015), Informant 2 said that he never felt burdened while taking care of his son. However, there were a few challenging situations for both caregivers, namely: (i) making decisions; (ii) routine changes; (iii) financial; and (iv) letting go.

#### ***Making Decisions***

Both Informants said that they always discussed before making any decision. However, Informant 2, as the head of the family, usually needed to make the final decision. For him, it was not always easy. For example, he had to decide on radiotherapy treatment and after cancer recurrence. Before the radiotherapy treatment, the specialist informed them of all possible consequences and side

effects. Informant 2 said that he decided for the doctor to cover half of the stomach to prevent damage to other organs. He said, "My son only has one kidney. If he recovers from cancer, and that kidney also damaged, it is also pointless. Therefore, I decided and requested to cover the right kidney during the treatment, do it on the left kidney only."

### ***Routine changes***

Another challenge faced by both informants was to adjust their routine during the treatments and to counter the side effects of the chemotherapy treatment. Informant 1 admitted that she needed to reduce their outdoor activities. According to her, her son's immune system was weak; therefore, he should not be too exposed to public areas. Hence, most of the activities with her son were done indoors. Furthermore, other changes they had to make included spending most of their time in the hospital, repeatedly commuting to the hospital for treatments, and being hospitalised. After knowing that her son was sick and needed special care, Informant 1 admitted that her sleeping routine also changed. She shared her challenges by saying, "While taking care of him, I will always be cautious even in my sleep." Informant 2 also shared, "Usually after return from chemotherapy treatments, two days after that, let us say the CT was on Wednesday, on Friday he will get a fever and his temperature increased. If the temperature is about 38 degrees, we need to immediately bring him to the hospital and warded for at least one week. Once, his body temp was almost 40 degree; his mouth got ulcers because his body was too hot. His lips cracked. He cannot eat because of that. He lost his appetite, and he lost his weight a lot."

Hence, her cooking styles also changed. One of the effects of cancer and its treatments, both informants said that their son had lost his appetite. The patient developed ulcers in his mouth and often vomited. His weight reduced drastically. As a mother, Informant 1 was concerned about this. To help her son cope with it, she would cook any food that her son wished to eat and able to eat. She said, "He also lost appetite for food. So, I need to take care of his nutrition." She added, "I cooked nothing special. Anything that is possible for him to eat. Even though just one bite."

As a father, Informant 2 said that his daily routine also changed when his son was hospitalised. He explained, "... the schedule for chemotherapy treatment was set up on Wednesday, so supposedly, I work from Monday to Friday, but I discussed with HOD and changed my working schedule. I took off on Wednesday and replaced it on Saturday..." He also said that he never missed visiting his son in the hospital even though the distance from the house or the workplace was far. He sacrificed his time, money, and energy to commute every

day, using public transport. He shared his experiences, saying, "The radiotherapy treatment occurred every day for 10 days. The treatment is in the morning, every day. So, I visited him every day for 10 days, and after that, I went to my workplace". He also added,

When he was warded again, I repeatedly visited him in the hospital and went to work, this happened for almost two weeks. I still work but finished at 4 pm. I took a train to the hospital after work. At night around 10 pm to 11 pm, I went home. The next morning, I went to my workplace and worked until evening.

### ***Financial***

The financial burden could be due to paying high medical expenses and losing income and savings (Deshields et al., 2012; Song et al., 2011). In this study, Informant 2 as the head of the family works to pay all expenses, including all the expenses needed during the treatments. Informant 1, as a housewife, did not contribute financially to support this family. However, as a Malaysian, the patient who was a primary school student has the privileged, and therefore, the treatments in HKL were fully funded by the Malaysian Government. Informant 2 said that he still managed to afford the expenses at the earlier stage because they received the treatment sponsorship from the government. However, the cost of the treatment increased when they stopped going for treatment at HKL and decided to get the treatment by themselves. Hence, other than depending on the monthly salary, the father also seeks financial help from his employer as he said, "I tried alternative medicine. During that time, I need extra money. I got financial support from my employer to buy the medicine, but it is expensive. I spent much money on that, thousands of ringgit."

### ***Letting Go***

The father could not hold his tears from flowing when he shared the last moments with his son on the day he passed away. Even though the doctor had told them that the son had no chance of surviving, and even though he knew it, but as a father, he still hoped that his son would survive. Unfortunately, the son's condition became critical; he was suffering and slowly dying. The father then finally 'understood' that it was time for him to give in and let his son go. Informant 1 also admitted that it was very hard for her when her son was dying and when he finally passed away. It was obvious that it had affected her deeply. During the interview, she could recall and describe the details of the moments very precisely. Her sharing is as follows:

On Thursday, he did not eat at all. My husband and I also only ate bread in the morning. Aqil was very weak. I can feel that he was dying. On that night, my husband left the ward to buy food for dinner. I prayed Isyak prayer very fast, and Aqil asked me not to leave him. I recited the Quran for him. In the middle of reciting the Quran, suddenly he woke up. His eyes were bright and very clear. I recited Surah Al-Ikhlas to him and led him to say syahadah. He said syahadah after me and became very weak again. His father was not there, I was waiting for him. I waited while leading him to say syahadah. Approximately 5 minutes later, when he saw his father opened the door, he called 'Abah!' and immediately hugged his father. He hugged his father very tight for a while. Then he said 'Allahuakbar' and passed away.

And finally, she ended her sharing of her son's last day by saying, "Almost at 10 pm, 29 May 2014, Friday night, 1<sup>st</sup> Syaaban."

### **Coping Mechanisms**

From the findings, two themes emerged from the focus on the coping mechanism, namely the internal support and external support. The internal support can be further divided into two categories, spiritually and emotionally; while the external support can also be divided into two categories, family members and non-family members.

#### ***External Support***

Family members in this study refer to the spouse, relatives, and the patient, while non-family members are the doctors/specialists, and employer/co-workers. Informant 1 believes that she was emotionally stronger compare to her husband as she said, "I am not sure, but I think my husband did not give any support." She also added, "I think, I am the one who gave him support," However, she admitted that her close family and the doctors gave her moral support as she said, "My family gave their support. Only them, no others." and "It was only the doctor who treated my son."

Besides, Informant 1 shared that her son also gave her strength. She expressed how she felt by saying, "I was strong because of him. If I said that I pity him, he would console me. He said that he is fine and do not say that." Like his wife, Informant 2 also said that his son's spirit gave him courage. He expressed his feeling saying,

My son, even though he was almost at the end of his life, his spirit was so strong. He still has ambitions. His planning for the future etc. Even though we knew his condition, but he still did not lose hope.

Informant 2 also admitted that the doctor helped him to accept the bad news in the beginning by giving counselling. Besides that, he received much support from his wife and his employer. He stated that his wife played an important role in helping him to cope with the challenges. Below are the excerpts, "My son stayed in the hospital with my wife, and she took care of him. I went to the hospital early in the morning. But, when I reached, they already entered the operation room". Whenever he felt sad, his wife was always by his side. He confessed, "I am not sure. It is just, I cannot be alone, I can't afford to miss him so much, I feel so sad. So, I avoid being alone, and my wife is always there for me."

Meanwhile, the employer helped him loosen up the work schedule. Not only the employer was supportive in terms of the work schedule, but he also provided financial support when Informant 2 was really in need. He expressed how lucky he was by saying, "For example, when I was working then suddenly my wife called because my son got high fever, I can immediately go home. My employer permitted me to leave; they are very understanding and always supportive." He also added that "I have no problem with my workplace because I had discussed with my HOD, and they gave me permission to change my working shift for 10 days." His employer not only being supportive in terms of work schedule but also provided financial support when he needed it. Informant 2 expressed it by saying, "...I tried alternative medicine. At that time, I need extra money. I received financial support from my employer to buy the medicine because it is expensive."

### ***Internal Support***

Informant 1 believes that she was emotionally stronger than her husband. Therefore, she said that most of the time, she helped herself to be stronger. From the findings, the researcher observed that from the beginning, Informant 1 preferred to keep her feelings to herself as she said, "I was shocked, but I hold myself and stay calm." She also never showed her sadness in front of other people, she added, "I gave him strength, but I cried in the washroom. In front of him, I tried to be strong." She also added that "Yes, I made myself strong, if I listen to other people, it just makes me feel angry. Because I think I read the Quran, I performed solat so, I already know."

Previous studies also showed that cancer patients usually experienced loss of well-being, severe tiredness, anxiety, drowsiness, hand numbness, mouth sores, appetite changes, depression, and shortness of breath, pain, and nausea (Akin & Durna, 2013). Therefore, the caregivers played crucial roles to overcome those symptoms. Findings from this study showed that both father and mother complement each other in providing treatments to their cancer-ridden son. Informant 2 also added that even though the challenges were difficult for him, he still managed to cope with them because it did not happen suddenly. He said that he was emotionally prepared because it took time. He explained,

One more thing, it does not happen (the death) in a sudden. Because we already know since the beginning and already expected the worst. I knew his chance is just 50-50; however, as a father, I always hope and pray that he will be fine. But still, at the same time, I also expected for the worst because I know cancer is not like other diseases.

Meanwhile, in terms of spirituality, both admitted that they are lucky for being Muslims. They believe that faith makes them strong and always positive. For example, Informant 2 explained, "It is an advantage for me as a Muslim because I believe 100% everything is from Allah. When thinking it is from Allah, automatically I stop feeling sad." He believed this is the fate from Allah SWT; He also believed that everything from Allah SWT is good for him, and as a Muslim, he must accept and resigned. He expressed his thought by saying, "If I cannot accept, I will feel very bad, sobbing and feel hard to accept the fact that my only son whom I loved so much, had been taken away from me." He added with tears in his eyes,

We accept fate. Because we are Muslims, we must be resigned, and accept that everything from Allah is the best for us. I accept and resigned for everything but, it is just that I miss him so much, I always remember our memories together.

Similar to her husband, Informant 1 also believed that Allah loves her son more than herself. Hence, she managed to cope with this test because she believed that this *dunya* is temporary, and all humankind will die sooner or later. She explained her beliefs by saying, "I always reminded myself that, if I was tested, other people were also tested worse than me. My test is nothing so, and I must be patient and accept that this is my part. I am powerless." She also believed that Allah loves her son more than herself as she said, "I have no right.

If I love him, Allah loves him more." She also managed to cope with this test because she believed that this dunya is temporary and because sooner or later all humankind will die. It showed in the finding when she extended, "One of my goals too. I know that one day I will die too. This test is preparation for me to go there. This world is just temporary." After all, she always prays and recites the Quran to make herself calmer.

## **Discussion**

A decade ago, many studies focused on female caregivers because it is common in many cultures, as stated by Kim et al. (2007). During that time, women were expected to be family caregivers; however, as time changes, this study found that both father and mother complete each other. Most of the responsibilities were shared by both father and mother, for instance; (i) provide treatment; (ii) making the decision; (iii) tender loving care (TLC); and (iv) provide emotional/spiritual support. This study confirmed the findings by other researchers that stated cancer patients usually experienced the loss of well-being, severe tiredness, anxiety, drowsiness, hand numbness, mouth sores, appetite changes, depression, and shortness of breath, pain, and nausea (Akin & Durna, 2013). As for the consequences, this study also found that the caregivers experienced some burdens, for instance, sleep disturbance and fatigue and pain as suggested by Fletcher et al., (2008) and Osse et al. (2006). Nevertheless, the caregivers still managed to play crucial roles while facing these challenges.

This current study agrees with Deshields et al., (2012), helping cancer patients in dealing with their feelings about cancer and providing emotional support for cancer patients are considered as difficult psychological tasks. Similarly, even though the findings from the interviews found that both father and mother played their roles well in providing emotional and spiritual support, it was not an easy task. Especially for this case study where the patient is the only child of the parents. Informant 2 believed that as a father, he needs to be strong in the presence of his son even though he is not very strong. He also confessed that he loves his son very much. Informant 1 also admitted that she silently wept in the washroom whenever she was unable to bear the sadness. However, strong faith in religion helped both caregivers a lot. As Muslims, praying and reading the Quran strengthened their spirits and helped them stay positive.

Previous researchers also found that the caregivers are burdened in many aspects including physical, psychological, social, and financial (Deshields et al., 2012; Rha, Park, Song, Lee, & Lee, 2015; Song et al., 2011), and this case study also have no exception. However, Informant 2, as the head of the family,

claimed that he never feels burdened while taking care of his sick son. The findings showed that the family managed to overcome the challenges not only because of their strong internal support, but also because they had steady external support. In terms of financial, as an example, a Malaysian primary school student receives a privilege from the Malaysian Government to fully-fund the treatments in HKL, including chemotherapy treatments, radiotherapy treatments, physiotherapy, and many more. The informant was also blessed with a supportive employer and co-workers. It helped them to reduce stress both directly and indirectly. The father was still able to work and earn money while taking care of his son with their cooperation and understanding.

Another interesting finding from the present study is even though the patient was sick and absent from the school for most of the year because of cancer; he still managed to score all A in the UPSR examination. According to French et al. (2013), children undergoing cancer therapy miss more school than they did in the year before their diagnosis and have absenteeism rates that are more than double compared to those of children with other chronic illnesses. However, the researchers found that the parents' roles are important to ensure the patient is not left behind even though he missed most of the classes. Arruda-Colli et al. (2015) suggested that there are six (6) coping strategies adopted by the family caregivers, namely (i) faith; (ii) family support; (iii) social support; (iv) perception of child's coping; (v) development of sense of power; and (vi) trust in the hospital institution. However, based on the findings of this case study, the researchers suggested that only two (2) main strategies arise, the internal support and external support. The researchers suggested that faith, perception, sense of power and trust in the hospital institution belong to the internal support category, while family and social fall into the external support category.

Even though some researchers claimed that spirituality and religiousness are distinguishable and not identical, albeit overlapping (Zinnbauer et al., 1999), in this case study, the researchers included religiousness together with spirituality. This is in line with the recommendation that stated there is a growing consensus that spirituality is the broader construct, encompassing all needs, attitudes, values, convictions, practices that transcend our material and objective world, especially as far as the meaning of life and hope are concerned (NICE, 2004). Thus, spirituality may be defined as a combination of religious and existential (non-religious, related to meaning and purpose in life) well-being (Laubmeier et al., 2004). Conversely, religiousness is a social phenomenon. Religions are defined by the borders of institutional belonging, belief systems, traditions, and practical commitments (Laubmeier et al., 2004). Hence, the

researchers agreed that spirituality and religious could be combined for this case study.

## Conclusion

Caregiving is typically something that people neither anticipate nor choose. However, like other parents, the parents in this case study take on this responsibility with little or no training and with limited resources. Thus, they experienced a considerable amount of challenges in their efforts to provide care for the cancer patient. Nevertheless, there are recommended coping strategies as proposed by previous studies and also confirmed by the current study to overcome those experiences and challenges. This paper offers an in-depth understanding of the challenges faced by the caregivers and how society supports them when facing those challenges in accordance with specific cultural and religious considerations. It is essential to consider the optimistic concepts, such as coping strategy as a foundation stone to those who are struggling with health challenges either directly or indirectly, especially in Asian societies, while focusing on their cultures, religion, and spirituality, to provide the necessary and appropriate understanding and support. Therefore, this study suggests that having strong supports; internally, and externally are the best combination to face any challenges and distress in life. As a Muslim, having strong faith in God is crucial to overcome obstacles in life.

## References

- Akin, S., & Durna, Z. (2013). A comparative descriptive study examining the perceptions of cancer patients, family caregivers, and nurses on patient symptom severity in Turkey. *European Journal of Oncology Nursing*, 17(1), 30–37.
- Arruda-Colli, M. N. F., Perina, E. M., & Santos, M. A. (2015). Experiences of Brazilian children and family caregivers facing the recurrence of cancer. *European Journal of Oncology Nursing*, 19(5), 458–464.
- Bahrami, N., Soleimani, M. A., Yaghoobzadeh, A., & Ranjbar, H. (2016). Researcher as an instrument in qualitative research: challenges and opportunities. *Advances in Nursing and Midwifery*, 25(90), 27–37.
- Bally, J. M. G., Holtslander, L., Duggleby, W., Wright, K., Thomas, R., Spurr, S., & Mpofu, C. (2014). Understanding parental experiences through their narratives of restitution, chaos, and quest: improving care for families experiencing Childhood Cancer. *Journal of Family Nursing*, 20(3), 287–312.
- Belgacem, B., Auclair, C., Fedor, M. C., Brugnon, D., Blanquet, M., Tournilhac,

- O., & Gerbaud, L. (2013). A caregiver educational program improves quality of life and burden for cancer patients and their caregivers: A randomised clinical trial. *European Journal of Oncology Nursing*, 17(6), 870–876.
- Coolbrandt, A., Sterckx, W., Clement, P., Borgenon, S., Decruyenaere, M., De Vleeschouwer, S., Mees, A., Dierckx De Casterlé, B. (2015). Family caregivers of patients with a high-grade glioma: A qualitative study of their lived experience and needs related to professional care. *Cancer Nursing*, 38(5), 406–413.
- Deshields, T. L., Rihane, A., Potter, P., Zhang, Q., Kuhrik, M., Kuhrik, N., & O'Neill, J. (2012). Psychosocial aspects of caregiving: Perceptions of cancer patients and family caregivers. *Supportive Care in Cancer*, 20(2), 349–356.
- Ferrell, B., Hanson, J., & Grant, M. (2013). An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psycho-Oncology*, 22(7), 1645–1652.
- Fletcher, B. S., Paul, S. M., Dodd, M. J., Schumacher, K., West, C., Cooper, B., ... Miaskowski, C. A. (2008). Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *Journal of Clinical Oncology*, 26(4), 599–605.
- French, A. E., Tsangaris, E., Barrera, M., Guger, S., Brown, R., Urbach, S., ... Nathan, P. C. (2013). School attendance in childhood cancer survivors and their siblings. *Journal of Pediatrics*, 162(1), 160–165.
- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21(3), 219–239.
- Given, B. A., Given, C. W., & Kozachik, S. (2001). Family Support in Advanced Cancer. *CA: A Cancer Journal for Clinicians*, 51(4), 213–231.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks: Sage Publications. Retrieved from [http://steinhardtapps.es.its.nyu.edu/create/courses/3311/reading/10-guba\\_lincoln\\_94.pdf](http://steinhardtapps.es.its.nyu.edu/create/courses/3311/reading/10-guba_lincoln_94.pdf)
- Kalapurakal, J. A., & Dome, J. S. (2015). Wilms' tumor. In L. L. Gunderson & J. E. Tepper (Eds.), *Clinical radiation oncology* (pp. 1422–1432). Philadelphia: Elsevier Health Sciences.
- Kendrick, K. D., & Robinson, S. (2002). "Tender loving care" as a relational ethic in nursing practice. *Nursing Ethics*, 9(3), 291–300.
- Keyton, J., King, T., Mabachi, N. M., Manning, J., Leonard, L. L., & Schill, D. (2004). *Content analysis procedure book*. Kansas: Lawrence, KS: University

- of Kansas.
- Kim, Y., Baker, F., & Spillers, R. L. (2007). Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *Journal of Pain and Symptom Management*, 34(3), 294–304.
- Krippendorff, K. (1984). Content Analysis: An Introduction to its Methodology. *Journal of the American Statistical Association*, 79(385), 240–244.
- Laubmeier, K. K., Zakowski, S. G., & Bair, J. P. (2004). The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International Journal of Behavioral Medicine*, 11(1), 48–55.
- National Cancer Institute (2016). Malaysian National Cancer Registry Report 2007-2011 - Malaysia Cancer Statistics, Data and Figure. *National Cancer Institute, Ministry of Health Malaysia*. Retrieved from <http://nci.moh.gov.my/index.php/ms/list-penerbitan/35-laporan/445-childhood-cancer-incidence-in-malaysia-2007-to-2011>.
- NICE. (2004). Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. NHS. London. Retrieved from [www.nice.org.uk](http://www.nice.org.uk).
- Osse, B. H. P., Vernooij-Dassen, M. J. F. J., Schadé, E., & Grol, R. P. T. M. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing*, 29(5), 378–388.
- Rha, S. Y., Park, Y., Song, S. K., Lee, Ch. E., & Lee, J. (2015). Caregiving burden and the quality of life of family caregivers of cancer patients: The relationship and correlates. *European Journal of Oncology Nursing*, 19(4), 376–382.
- Senden, C., Vandecasteele, T., Vandenberghe, E., Versluys, K., Piers, R., Grypdonck, M., & Noortgate, D. (2015). The interaction between lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: A qualitative study. *International Journal of Nursing Studies*, 52(1), 197–206.
- Song, J. I., Shin, D. W., Choi, J. Y., Kang, J., Baik, Y. J., Mo, H., Park, M. H., Choi, S. E., Kwak, J. H., & Kim, E. J. (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Supportive Care in Cancer*, 19(10), 1519–1526.
- Turner, D. W. (2010). Qualitative Interview Design: A Practical Guide for Novice Investigators. *The Qualitative Report*, 15(3), 754–760.
- West, C. H., Bell, J. M., Woodgate, R. L., & Moules, N. J. (2015). Waiting to return to normal: An exploration of family systems intervention in childhood cancer. *Journal of Family Nursing*, 21(2), 261–294.

Zinnbauer, B. J., Pargament, K. I., & Scott, A. B. (1999). The emerging meanings of religiousness and spirituality: problems and prospects. *Journal of Personality*, 67(6), 889-919.

Date Received: 12 April 2018      Date of Acceptance: 15 November 2019