

# Journey of Recovery: Challenges and Coping Resources of a Cancer Survivor and Caregiver

Ong Chia Mian<sup>a</sup>, Tan Joo Siang<sup>a\*</sup>, Aminabibi Saidalvi<sup>b</sup>

<sup>a</sup>Department of Educational Studies and Behavioral Sciences, Faculty of Educational Sciences and Technology, Universiti Teknologi Malaysia, 81310 UTM Johor Bahru, Johor, Malaysia

<sup>b</sup>Academy of Language Studies, Universiti Teknologi MARA, Pasir Gudang Campus, 81750 UiTM, Masai, Johor, Malaysia

\*Corresponding author: joosiang@utm.my

**Article history:** Received: 11 February 2025 Received in revised form: 01 April 2025 Accepted: 07 May 2025 Published online: 31 October 2025

## Abstract

Living with cancer is challenging. The journey of treatment and recovery can be a daunting experience for individuals with cancer as well as caregivers. Studies have shown that cancer survivors' coping strategies and the support received were keys to recovery. Hence, this research aims to explore the challenges faced by cancer survivor and caregiver, their unmet needs, coping strategies, support and changes they have discovered during the recovery journey. A qualitative research method was adopted where a cancer survivor and a caregiver were chosen purposively. Both of them were interviewed separately in order to understand their experience in an in-depth manner. The data was transcribed and analysed with thematic analysis aided by Nvivo 12. Data was triangulated through member checking, informants' and experts' validation. Informal observation, newspaper articles and social media communication were referred to ensure the trustworthiness of the data. The findings show that both cancer survivor and caregiver were overwhelmed with negative emotions. However, both parties entrusted their beliefs to God and combated the disease with perseverance and optimism. Their personality, coping strategies and support received from family, friends and communities were their main resources. This study suggests that forming supportive communities and involving mental health professionals enable both individual with cancer and caregiver to face the disease in a more proactive manner.

**Keywords:** Cancer survivor, caregiver, challenges, cope with cancer, resources, qualitative research

## Abstrak

Kehidupan bersama kanser dianggap sebagai mencabar. Perjalanan rawatan dan pemulihan boleh menjadi pengalaman yang menakutkan bagi pesakit kanser serta penjaga. Kajian menunjukkan bahawa strategi menangani kanser dan sokongan yang diterima oleh pesakit adalah kunci pemulihan. Oleh itu, penyelidikan ini bertujuan untuk meneroka cabaran yang dihadapi oleh pesakit kanser dan penjaga, keperluan mereka yang tidak terpenuhi, strategi mengatasi, sokongan dan perubahan mereka dalam perjalanan pemulihan. Kaedah penyelidikan kualitatif telah digunakan dan kedua-dua survivor kanser dan penjaga dipilih secara bertujuan. Kedua-duanya ditemuduga secara berasingan untuk memahami pengalaman mereka secara mendalam. Data ini ditranskripsi dan dianalisis dengan analisis tematik yang dibantu oleh Nvivo 12. Data ditriangulasi melalui pemerhatian, artikel akhbar dan komunikasi media sosial. Pemeriksaan ahli dan pengesahan responden dan pakar telah digunakan untuk memastikan kesahihan data. Dapatan kajian menunjukkan bahawa pesakit kanser mengalami kesakitan fizikal akibat kesan sampingan dan kedua-dua pesakit kanser dan penjaga mengalami emosi negatif. Walau bagaimanapun, kedua-dua pihak memberikan kepercayaan mereka kepada Tuhan dan memerangi penyakit kanser secara sabar dan optimis. Personaliti, strategi mengatasi dan sokongan yang mereka terima daripada keluarga, rakan dan komuniti adalah sumber utama mereka. Model Tekanan dan Sumber Mengatasi telah dicadangkan untuk menerangkan kesan stres akibat kanser dan sumber dalam menangani stres oleh pesakit kanser dan penjaga semasa proses pemulihan. Kajian ini mencadangkan pembentukan komuniti yang menyokong dan penglibatan profesional kesihatan mental membolehkan pesakit kanser dan penjaga menghadapi penyakit dengan cara yang lebih proaktif.

**Kata kunci:** Survivor kanser, penjaga, cabaran, menghadapi kanser, sumber, kajian kualitatif

© 2025 Penerbit UTM Press. All rights reserved

## 1.0 INTRODUCTION

The prevalence of cancer is one of the major causes of mortality all over the world. In the latest report shown by World Health Organization ([WHO], 2024), there were approximately 20 million new cases and 9.7 million cancer-related deaths worldwide. More than 4 million women died from cancer resulting to more than 1 million children became maternal orphans (International Agency for Research on Cancer [IARC], 2023). Cancer has become the third most common cause of death in Malaysia with 168,823 cases reported in the recent Malaysian National Cancer Registry Report 2017-2021 with the probability of an individual developing cancer before the age of 75 years in the absence of other causes of death for both males and females increased to 1 in 8 (National Cancer Registry Department [NCRD], 2023). However, under-reporting is always a noteworthy problem in such surveys (Jeffree et al., 2016; Lim, 2002), thus, the estimation for the new cancer cases is likely to be more than the incidence rate as shown in the official report.

Encouraging results of research have shown that the number of people living after a cancer diagnosis is steadily increasing in many countries partly owing to the early detection and treatment advances (DeSantis et al., 2014; de Moor et al., 2013; Guzzinati et al., 2018;

Herrmann et al., 2013). Owing to the heightened survival rates in individuals with cancer, most cancer survivors are now having prolonged period of stay with this incurable but controllable illness. However, the journey from being a cancer patient towards a cancer survivor is full of fear (Custers et al., 2016; Farooqui et al., 2011; Marieke et al., 2016; Taib et al., 2011; Williams & Jeanetta, 2015) and uncertainty (Miller, 2012; Yusuf et al., 2013a). Throughout the journey of combating the disease, cancer treatment has a great impact on individual with cancer, as well as their caregivers and family members. Undergoing cancer treatment and caring for individuals with cancer can be highly stressful, often inducing negative emotional responses that impact both the physical and psychological well-being of the patients, as well as their caregivers and family members (Fereidouni et al., 2024). To address these challenges, understanding the recovery journey of cancer survivors and caregivers is crucial for identifying the resources needed in cancer care support. Specifically, it is important to integrate relevant and innovative counselling and mental health care that are tailored to the unique needs of individuals with cancer. Therefore, this research aims to explore the perspectives of a cancer survivor and their caregiver on the cancer recovery journey.

## ■2.0 LITERATURE REVIEW

Several factors caused the emotion of fear among individuals with cancer. Some patients claimed to feel afraid of the disease itself and therefore refuse to accept the diagnosis (Taib et al., 2011) while some patients indicated their fear of surgery and the side effects of therapies which inhibit them from seeking conventional treatments (Farooqui et al., 2011). On the other hand, the source of fear for most of the cancer survivors was mainly due to potential recurrence of cancer. Owing to fear of recurrence, some of the breast cancer survivors shared that they had opted for the most “aggressive treatment” – surgeries to eliminate the risk of re-encountering cancer even though the health care providers had assured a low probability of recurrence (Williams & Jeanetta, 2015).

Miller (2012) discovered the sources of uncertainty included medical, personal and social aspects among 35 cancer survivors and 25 partners. Besides fear and uncertainty, there are serious impacts on the individuals with cancer after receiving treatments. In fact, the course of the treatment affected them physically, psychologically and cognitively. Physically, they experienced adverse effects such as tiredness or fatigue, pain, nausea, breathlessness as the consequences of treatments (Tan et al., 2012; Yusuf et al., 2013b). Emotionally, some of them had fear, worry and depression (Tan et al., 2012). In a systematic review of observational studies, Zainal et al. (2013) reported that the prevalence of depression among breast cancer survivors shown in Asian studies fluctuated from 12.5% to 31%. Moreover, some patients encountered concentration problem, forgetfulness and slower rate in information processing (Biegler et al., 2009; Tan et al., 2012). As the results, the side effects of the treatments hindered the process of their transition to normal life, especially for those who were returning to the workforce (Mak et al., 2014; Tan et al., 2012).

Despite the stressful journey, a number of studies showed that individuals with cancer developed various methods to cope with the critical life situation, including being optimistic and turning to religion or spirituality. In a quantitative study conducted in New York among 168 individuals with advanced cancer (Applebaum et al., 2014), results shown that individuals with higher levels of optimism were significantly related to fewer symptoms for anxiety and depression, less hopelessness and better quality of life. Another study also showed that optimism was associated with better quality of life among colorectal cancer survivors with after a 5-year diagnosis (Chambers et al., 2012).

Some cancer survivors turned to religion or/and spiritual to gain psychological comfort. In a study conducted among 155 African American breast cancer survivors (Davis et al., 2016), almost all the participants placed spirituality as their central role throughout their survivorship. In another study, when being in dilemma to make a decision for treatments, some patients claimed that they had prayed to God to guide them to a correct direction (Yusuf et al., 2013a). Besides, the findings of a study conducted by Vivien, Er and Noor (2013) among 50 Chinese participants provided evidence that individuals with cancer had turned to religion under the situation of existential threat.

Another crucial resource to help buffer cancer survivors from having psychological distress and unconstructive thoughts was having supportive social relationships. Cancer survivors recounted that the support systems comprising family members, friends and other people in their social contexts had provided them with strength and courage to pass through the different phases of recovery journey (Williams & Jeanetta, 2015; Yusuf, 2013). Ng et al. (2015) found that the perceived social support resulted in better quality of life and low levels of depression and anxiety among the informants. Hu et al. (2019) emphasized the importance of providing dyadic interventions to both individuals with cancer and their family caregivers, as their research demonstrated its positive impact on improving patient outcomes across various psychosocial aspects. However, such explorations remain limited in Malaysia.

Except the above support systems, owing to the increased penetration rate of internet in people's daily life, cancer survivors also received support from online community, such as Facebook group (Bender et al., 2011; Setoyama et al., 2011). Social media has increasingly played a vital role in providing additional resources for individuals with cancer. Wang et al. (2023) examined the mediating effects of online social support and psychological resilience in the relationship between social media use and the mental health of individuals with pancreatic cancer, yielding positive and significant results.

In Malaysia, the studies related to individuals with cancer and cancer survivors were mostly conducted by researchers in the field of medicine while studies on this particular vulnerable group of people from the psychosocial aspect were scarce. In view of this, the aim of this study was to understand the challenges met by a Malaysian cancer survivor and his caregiver and their key resources to cope with the treatment process. By collecting perspectives from both cancer survivor and caregiver, an overview of the cancer recovery journey was gained.

## ■3.0 METHODOLOGY

Qualitative research is an appropriate approach for gaining in-depth insights from individual experiences (Creswell & Creswell, 2023). Thus, this study employs a qualitative method to explore the experiences of a cancer survivor and his caregiver throughout the recovery journey. A purposive sampling method was employed to recruit the informants. A dyad consisting of a cancer survivor and his family

member who had played as his main caregiver during the recovery process was recruited. The inclusion criteria for the cancer survivor and caregiver were 18 years old and above and must have the ability to express their opinions clearly and willingness to share their exclusive experiences. A protocol for interview guide consisting of several key questions was designed. The protocol was reviewed by an expert and tried out with a cancer survivor for a pilot interview. Feedback was obtained and the protocol was amended accordingly.

Informed consent was obtained from both informants prior to conducting the semi-structured in-depth interviews, ensuring they were fully aware of the study's purpose, procedures and their right to withdraw at any time without any negative consequences. Following consent, the interviews were conducted sequentially in a private setting at their convenience to ensure confidentiality and privacy. Additionally, with the cancer survivor's consent, supplementary documents including newspaper articles and social media posts were collected to provide a comprehensive understanding of his experiences from various perspectives.

Soon after each of the interview sessions, the audio tape was transcribed using Nvivo (version 12.0). A thematic analysis was employed. First, after having immersed in the transcript, the researcher extracted the text into segments and quoted them by stating their underlying meaning without making any interpretation. Second, similar quotes were grouped while redundant quotes were eliminated. Third, similar subthemes were categorised into themes to identify the consistent patterns of meaning throughout the dataset. Finally, answers for the research questions were addressed after a review of themes were conducted.

In order to ensure the trustworthiness of the results, peer checking, expert review and validation from informants were conducted. A peer was requested to conduct the same stages of data analysis as the researcher did, namely coding the text segments, categorising the codes into sub-themes and merging the sub-themes into themes. In addition, meeting with the researcher to discuss the agreement and disagreement on the codes, subthemes and themes were conducted.

Besides, an invitation to review the codes and themes generated from the qualitative data were held with two graduate faculty members who have experience conducting qualitative research studies. The agreement between two experts towards the codes were collected, and the Cohen's kappa coefficient (k) for cancer survivor's coding was 0.97 while for caregiver's coding was 0.96.

#### ■4.0 RESULTS

This research involved a cancer survivor who was cared for by his mother. The cancer survivor, single, was diagnosed nasopharyngeal cancer, stage 3 when he was 37 years old in year 2013. He went through chemotherapy and radiation therapy. After recovery, he has worked in a non-governmental organisation to provide support for cancer patient and their family members. Throughout his recovery journey, his mother served as his main caregiver. She is a widow and her husband passed away in year 2016. She has four children and she takes care of her grandchildren during daytime. She is active in practicing Wai Dan Kung (a type of Chinese Qigong) with her friends in the park and she is often a volunteer in her religious organisation.

Both the cancer survivor and his mother faced significant challenges throughout the treatment and caregiving process. Despite their struggles and pain, they found ways to cope through their religious and spiritual beliefs, as well as support from family, friends, and the community. The following interview excerpts illustrate their unique journey through cancer treatment and recovery.

##### 4.1 Challenges met by the cancer survivor

The challenges met by the cancer survivor can be divided into two parts, namely physiological and psychological effects. The side effects of the treatment brought adverse effect on his body, such as non-stop vomit, loss of saliva, loss of taste, tinnitus, dizziness, headache, insomnia and burning of oral and ulcer in throat. The following excerpts were his descriptions of his condition after completing the radiation therapy in the second week.

*"The biggest challenge was... undergoing the radiation therapy in the second week of the treatment. I really... had no strength to stand and I need to lend support from things to stand up. (I) kept vomiting until my gastric acid was thrown up..." (SP8-311)*

*"When being burnt (by the radiation therapy), that time was very difficult because it burnt my mouth, including my throat was ulcerated...ulcerated. When taking food, (I) felt painful and (I) also felt painful even when I was drinking water." (SP4-152)*

The cancer survivor described intense physical suffering during radiation therapy, including extreme weakness, persistent vomiting, gastric distress, mouth and throat ulcers and severe pain when eating or drinking.

When suffering from the physiological discomfort, he was experiencing negative emotions followed by his negative thoughts. He mentioned his anger towards his body reaction and thought of giving up in the following excerpts.

*"(I) felt angry towards my body which was disobedient and always reacted like this until I felt very awful." (SP10-359)*

*"Ah, forget about it. Don't let me undergo treatment and just let me die will do! Stop undergoing (it)... (it) was so painful!" (SP3-101)*

These debilitating symptoms triggered strong negative emotions, such as anger toward his own body and triggered his thoughts of abandoning treatment and accepting death due to the overwhelming pain.

##### 4.2 Challenges Met By Caregiver

The main challenge for the caregiver was experiencing negative thoughts and emotions from the beginning of recovery journey until life after the completing of the treatment process. She believed that having cancer was desperate and hopeless as her mother died due to cancer as well.

*"Because my mother was... cancer, so I felt umm... very scared of this disease. Once I heard this disease, I feel like I was desperate." (CP3-101)*

During the treatment process, the caregiver felt heartache whenever she sees her son vomiting and was always worried that it would hurt his body. Simultaneously, some negative thoughts emerged in her mind.

*"I was afraid that he might vomit too seriously... also afraid... also afraid that he vomited... and did not know what would happen to his body? Because when you saw him vomit like this, you would continue thinking nonsense. Although there was nothing, you kept thinking there would be something..." (CP11-398)*

Besides, she felt helpless when she did not know how to provide help to her son, especially when he kept vomiting after treatment. She kept on sobbing whenever she thinks of the difficulties her son was undergoing even while doing house chores.

*"While doing, (I) kept thinking. While thinking, (I) kept sobbing! (Laugh) Doing and thinking at the same time... Wow... thinking that... Oh (I) did not how to do and thus I kept sobbing." (CP6-205)*

In the hospital, if she sees patients passing away, it would affect her and she tended to associate with her son by "what if".

*"For example when you (I) went to... elsewhere, you (I) saw that person suddenly passed away, wow... you (I) would feel a bit dejected. Oh, what happened to him? (I) would think, 'Oh, if he (her son) passed away, it would be miserable..." (CP11-420)*

After the treatment, although her son has recuperated, she is still feeling uncertain and worried that he might suffer relapse. The feelings of fear increases, if her son has fever.

*"However, it has just passed a few years (and thus) I worry it every day! (I) worry whether it will come back. What if it comes back, how are we going to face it? (I) always have this question mark!" (CP10-366)*

#### 4.3 Cancer Survivor's Key Resources To Cope With Treatment Process

Personal resources and support from others were the cancer survivor's key resources to cope with the treatment process. In view of his personal resources, he tended to focus on solving problems since he was informed of his cancer diagnosis and the following excerpt illustrates his plan for his situation.

*"The first (I) thought was... after completing treatment, I could go back to continue my original life; second, if the treatment was not successful, I needed to get ready to bid goodbye. So... (I) only had these two thoughts, these two thoughts only..." (SP30-1110)*

Besides, he tended to bear the responsibilities to make him feel better for his condition. The following excerpts show the action he performed to care for himself.

*"Before undergoing the treatment, I had already had my hair shaved as I thought I could save those troublesome matters." (SP2-66)*

*"Normally if (I) felt bored during treatment process, I would ask my friend out or go to watch movie at cinema. Watching movies at cinema was actually good as watching movies actually... Why did some people weep when watching movies? This was because they had the same feelings as the characters in the movies had and also thought that... this was a channel to express their emotions..." (SP14-507)*

The cancer survivor had opportunities to expose himself in two different religious beliefs, namely Buddhism and Christianity. He was able to be more rationale when facing the disease as he believed in "karma" and he knew that having sickness was just a life process. In addition, his belief on God that human is created with wisdom motivates him to overcome his difficulties. The following excerpts elucidate how these two religious beliefs supported him during his treatment process.

*"In Buddhism, (they) taught us that actually birth, old age, sickness and death is a life process which we have to face. Therefore, I didn't feel anything but just to face it will do..." (SP8-293)*

*"The God, so He will give us wisdom and through the education he gave us a mindset... to break through, to overcome (difficulties)... What the true religion let me experience was that I was in the sea, I was not looking for the lifebelt but I was learning how to save myself and how to swim." (SP29-1070)*

Throughout the process, the cancer survivor was perseverant when experiencing the side effects of the therapy. He forced himself to consume some food and endured the pain whenever he felt uncomfortable. The following excerpts illuminate how perseverant he was to maintain his food intake although he kept throwing up the food he had eaten. He forced himself to consume some food and endured the pain whenever he felt uncomfortable.

*"I forced myself to hold on to it. I was really dying to make it. During that time, (I) was really dying to make it. (I) kept vomiting... vomiting until I couldn't endure anymore... vomiting... holding the toilet bowl and vomiting..." (SP9-328)*

*"I actually... forced myself all the way... uh... to eat as much as I could. Ate then vomited, vomited and see how then..." (SP3-86)*

Besides his personal resources, the support provided by his main caregiver, family members, employer, healthcare providers and friends facilitated the cancer survivor's recovery journey. His mother serving as his main caregiver attended to his needs at night while during daytime she was busy on taking care of him and preparing healthy food for him. The following excerpts described his mother's routine while taking care of him.

*"Took a number and came back... Saw the doctor and came back umm... (he) lay in his room, (I) checked on his condition and prepared some food for him to eat a little bit..." (CP10-378)*

*"I...I couldn't sleep tight all night long. On the whole, when he was sleeping, I would go into his room once every one or two hours." (CP5-182)*

His previous employer (the company he was in when he was diagnosed cancer) suggested him remaining his job position and taking hospitalisation leave while he was undergoing the treatment process. It certainly reduced his financial burden.

*"Human Resource Department had a discussion with our boss. Our boss was nice too. He allowed me to keep my position and they still hoped that I could continue my work there after completing the treatment. Therefore... according to Malaysian Employment Act, (I) then rested for two months by using the... so-called hospitalisation leaves and that was considered paid leave." (SP22-813)*

Finally, he felt supported when referring to celebrities' inspiring experiences – their stories brought about his thought that having cancer was just merely a disease and there was nothing that he could not face.

*"...Another person who gave me much reflection... encouraged me a lot mentally, one is called that... he did publish a book... he is called Nick, a person with disabilities and he is a Christian as well. He doesn't have hands and legs but he can face his life openly and calmly, and he has even got married and had a kid! I would think that there was nothing which I could not face. Having cancer actually... we said that having cancer actually was just a disease only." (SP18-662)*

#### 4.4 Caregiver's Key Resources To Cope With Treatment Process

The key resources for the caregiver to cope with the caregiving process included personal resources and support from others. With regards to her personal resources, she tended to focus on finding solutions for the problems after she was informed of her son's diagnosis. She also tried to refer to other patients' situations and consult nurses in order to understand her son's condition and know how to help him.

*"Sometimes you needed to go... around to look at others' condition, thus you would... would know how it was. Therefore, I went to see this and that!" (CP11-407)*

In order to reduce her worry, she took care of her son actively on her own. She felt a bit more relieved when doing so.

*"It seemed that if I could take care of him by myself, then he would recover faster..." (CP11-457)*

She tended to believe in fatalism – she thought that it was arranged by fate to decide whether the treatment would be effective and his son would recover. Also, she reasoned that probably life was destined with difficult situations.

*"Perhaps life was to go through this! Ah, no choice, (we) need to work hard! No matter how painful it was, (we) need to endure." (CP9-327)*

Throughout the recovery process, the caregiver was perseverant and took good care of her son – she did not care whether the tough situation made her worn out and her hopes were to give her son confidence so that he could pass through the process.

*"Never mind, never mind if I was exhausted. I could solve it by myself. They... (I) must give them... to have that... to have confidence... (I) must give them this!" (CP16-594)*

Besides, she tended to be optimistic and hopeful when thinking of her son's situation. After comparing to other patients' condition, she realized that others with more serious condition succeeded and thus believed that her son would succeed as well.

*"Like when I saw his condition, tsk... I looked at the patient next to him... the patient was so serious while my son was like this. Comparing them, others could overcome, why not my son?" (CP11-414)*

*"(I) tended not to think too much and console myself. Wow, he was going to be fine! (I) kept on thinking that he was going to be fine. Once the water finished, then the second would be replaced and he would be fine." (CP11-416)*

The support received from others also helped the caregiver cope with the treatment process. When taking care of her son, she received assistance from her husband and sister to send her back and forth to the hospital.

*"Luckily my sister helped me. She sent me (to the hospital) every morning. During that time, my husband was still alive, their father was still alive, and his father sent me to the hospital to take the number." (CP10-363)*

Also, she felt grateful for the concerns showed by her friends.



*“Because... there had been people who showed their concerns. (They) concerned and paid visit, I felt... tsk... not bad...”*  
(CP17-627)

## ■5.0 DISCUSSION AND RECOMMENDATION

This research aimed to understand the cancer survivor's and caregiver's challenges and key resources to cope with the treatment process during the recovery journey. The first challenge for cancer survivors was always the cancer diagnosis. Upon receiving the diagnosis, some individuals with cancer tend to make sense of the illness through religious appraisal, viewing it as a reminder from God to draw closer to Him (Ahmad et al., 2011; Ahmadi et al., 2018). In this research, the cancer survivor trying to make sense of the disease – besides identifying the reasons of his cancer, he took the disease as a gift from God and which was to make him stronger so that he knew how to face his life better. With this positive appraisal, he was able to accept the disease and take initiative to cooperate with health care providers and caregiver for his recovery process. Similarly, religion was also highlighted by individuals with breast cancer as an important factor in helping them cope more effectively with their illness (Daniah MB et al., 2021).

Although some cancer survivors managed to accept the disease, the agonising side effects which elicited different degree of discomfort and pain sometimes provoked their thought of giving up. In view of this, there was a great struggle between fighting with cancer and giving up the treatment process. It was similar with the fight-or-flight response which is a physiological reaction regulating stress responses when individuals perceived harmful events or threats (Cannon, 1915). In this situation, the sympathetic nervous system will prepare individuals either fight with or flee from the stressors. Despite the pain and side effects, the survivor shared that the support from his mother, other family members and friends gave him the strength to endure the physical suffering. Past research has highlighted the importance of social support as a strong determinant of patients' well-being and quality of life (Chen et al., 2023; Sauer et al., 2019; Tian et al., 2021). However, research by Sauer et al. (2019) highlighted the importance of recognising both the positive and negative aspects of social support in preventing psychological symptoms and dyadic stress among individuals with cancer and their family members. Therefore, providing psychological support to both patients and caregivers is essential in alleviating the stress and burden associated with cancer care and coping for all parties involved.

Combating cancer can be less distressing with environmental support possessed by the cancer survivor. In view of this, the Ecological Systems Theory (Bronfenbrenner, 1979) can serve as a reference to understand the effective elements to facilitate cancer survivor treatment process. For example, in the individual level, cancer survivors' personal qualities and strong will to stay alive affected their behaviours to fight the disease; in microsystem, the care and support provided by family members and friends and the treatment offered by the health care providers were crucial for cancer survivors to recover from the disease; in mesosystem, the interaction between caregiver and family members and between caregiver and health care providers affected the quality of care rendered; in exosystem, the support and concern given to the caregivers helped relieve their stress and which might provide more strength to cope with the caregiving process; lastly in macrosystem, the subsidy provided by the Malaysian government for health care services and the policy on Employee's Provident Fund (KWSP) and Social Security Organisation (SOSCO) helped relieve cancer survivors' financial burden.

Moreover, it is worth mentioning that online cancer support groups have become an emerging trend among individuals with cancer and their caregivers for accessing information and obtaining support. Facebook groups serve multiple purposes including fundraising and support-seeking for those affected by cancer (Bender et al., 2011). In a study investigating the functions of Instagram, Zade et al. (2017) found that the platform fulfilled several roles in helping individuals cope with the disease. Individuals with cancer commonly sought information related to cancer, treatment options, management of side effects, and overall health advice through social networks. Additionally, emotional and social support was gained from the shared experiences of other survivors. Posting questions and receiving responses helped individuals better understand their condition, leading to a sense of peace and reducing feelings of isolation and loneliness. Further research is needed to explore the functions and implications of various online platforms that cater to diverse groups of individuals living with cancer. More training should focus on the utilisation of technology and research should be conducted on the effects of software application as well as technologies involving virtual reality and simulations (Fernando, 2020).

Fernando (2020) exerted the unmet needs of mental health support for individual with cancers and urged for more effective integrations of services into the current cancer care services involving patient choice and clinical requirements. In this research, the researcher has found that both cancer survivors and caregivers struggled throughout the recovery process. Therefore, a third party, namely counsellors and psychotherapists, can play a crucial role to provide psychosocial interventions to help promote adjustment, thereby enabling them to face the disease in a more proactive manner. For example, the hospital and cancer organisation in the society can involve counsellors to conduct group counselling for individuals with cancer and caregivers respectively and family counselling for the family in order to provide psychosocial interventions for people in need. Gibbons et al. (2019) highlighted that role adjustment and mutuality are key facilitators of growth for both individuals with cancer and their caregivers as they navigate the complex journey of cancer treatment and caregiving.

Jevne et al. (1998) introduced a model for counselling individual with cancer that integrates the cancer experience within a counselling framework that put greater emphasis on individuals, combines problem solving approach with a biopsychosocial perspective to empower patient. It is essential for counsellors to be sensitive to unique experiences of individual with cancer in the recovery journey while providing counselling services. Counselling individuals with cancer also involves addressing spiritual concerns and demonstrating multicultural competence (Voon & Chan, 2021). Understanding their emotional struggles and moral dilemmas is crucial when providing effective support. Moreover, involving cancer survivors and caregivers who wish to help others with similar experiences can offer a meaningful platform for connection and encouragement. Sharing stories of resilience not only fosters hope but also helps individuals facing cancer to regain confidence by learning from those who have overcome similar challenges.

## 6.0 CONCLUSION

This research aims to provide preliminary information for counsellors, palliative care providers and caregivers to understand further the experiences of cancer survivor and caregiver. The struggle met by cancer survivor and the intense interaction between both parties informed the stakeholders to think of ways to support them during the recovery process, for example, helping the individuals with cancer alleviate the pain they suffer, educating caregivers to provide better care for the patients, providing a respite for caregivers while looking after the patients and so on.

For future studies, a bigger sample size of the informants with diverse background, genders, socioeconomic status, marital status and educational level is required to provide a broader view of this phenomenon. Future research may consider conducting dyad interview (Morris, 2001) combining individual and joint interviews with cancer survivors and caregivers concurrently to offer a more in-depth and valuable method of enquiry. Topics related online support system are worthy to be explored as most people, including individuals with cancer and caregivers, have relied heavily on resources online shared by others who have similar experiences. The research on this phenomenon will shed light on a new potential way for health care providers, counsellors and relevant authorities to reach out and provide help for individuals with cancer and their family members.

## Acknowledgement

The authors would like to thank all the participants for sharing their journey with us and express their gratitude to Universiti Teknologi Malaysia (UTM) for supporting this project.

## Conflicts of Interest

The author(s) declare(s) that there is no conflict of interest regarding the publication of this paper

## References

- Ahmad, F., Muhammad, M. & Abdullah, A. A. (2011). Religion and Spirituality in Coping with Advanced Breast Cancer: Perspectives from Malaysian Muslim Women. *Journal of Religion and Health*, 50, 36-45. DOI:10.1007/s10943.010.9401.4
- Ahmadi, F., Mohamed Hussin, N.A. & Mohammad, M.T. (2018). Religion, Culture and Meaning-Making Coping: A study among Cancer Patients in Malaysia. *Journal of Religion and Health* 58, 1909–1924. DOI: doi.org/10.1007/s10943-018-0636-9
- Applebaum, A. J., Stein, E. M., Lord-Bessen, J., Pessin, H., Rosenfeld, B. & Breitbart, W. (2014). Optimism, Social Support, and Mental Health Outcomes in Patients with Advanced Cancer. *Psychooncology*, 23 (3), 299-306.
- Bender, J. L., Jimenez-Marroquin, M. C., & Jadad, A. R. (2011). Seeking support on facebook: a content analysis of breast cancer groups. *Journal of medical Internet research*, 13(1), e16. DOI: https://doi.org/10.2196/jmir.1560
- Biegler, K. A., Chaoul, M. A. & Cohen, L. (2009). Cancer, Cognitive Impairment and Meditation. *Acta Oncol*, 48 (1), 18-26. DOI:10.1080/02841860802415535
- Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. UK: Harvard University Press.
- Cannon, W.B. (1915). *Bodily Changes in Pain, Hunger, Fear, and Rage*. New York: Appleton-Century-Crofts.
- Chambers, S. K., Meng, X., Youl, P., Aitken, J., Dunn, J. & Baade, P. (2012). A Five-year Prospective Study of Quality of Life After Colorectal Cancer. *Qual Life Res* 2012, 21:1551-1564. DOI:10.1007/s11136.011.0067.5
- Chen, C., Sun, X., Liu, Z., Jiao, M., Wei, W., & Hu, Y. (2023) The relationship between resilience and quality of life in advanced cancer survivors: multiple mediating effects of social support and spirituality. *Front. Public Health* 11, 1207097. DOI: 10.3389/fpubh.2023.1207097
- Creswell, J.W., & Creswell, J.D. (2023). *Research design: Qualitative, quantitative, and mixed methods approaches* (6<sup>th</sup> ed.). Sage.
- Custers, J., Gielissen, M., Janssen, S., de Wilt, J., & Prins, J. B. (2016). Fear of cancer recurrence in colorectal cancer survivors. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer*, 24(2), 555–562. DOI:10.1007/s00520-015-2808-4
- Davis, C. M., Myers, H. F., Nyamathi, A. M., Lewis, M., & Brecht, M. L. (2016). The Meaning of Survivorship as Defined by African American Breast Cancer Survivors. *Journal of Transcultural Nursing*, 27 (3), 277-285. DOI:10.1177/1043659614561678
- De Moor, J. S., Mariotto, A. B., Parry, C., Alfano, C. M., Padgett, L., Kent, E. E., ... Rowland, J. H. (2013). Cancer Survivors in the United States: Prevalence across the Survivorship Trajectory and Implications for Care. *Cancer Epidemiology, Biomarkers & Prevention*, 22(4), 561-570. DOI:10.1158/1055-9965.EPI121356
- DeSantis, C. E., Lin, C. C., Mariotto, A. B., Siegel, R. L., Stein, K. D., Kramer, J. L., ... Jemal, A. (2014). *CA Cancer Journal for Clinicians*, 64, 252-271. DOI:10.3322/caac.21235
- Farooqui, M., Hassali, M. A., Shatar, A. K., Shafie, A. A. Tan, B. S. & Farooqui, M. A. (2011). A Qualitative Exploration of Malaysian Cancer Patients' Perspectives on Cancer and Its Treatment. *BMC Public Health* 2011, 11:525. DOI:10.1186/1471.2458.11.525.
- Fereidouni, Z., Dehghan Abnavi, S., Ghanbari, Z., Gashmard, R., Zarepour, F., Khalili Samani, N., ... Ghasemi, A. (2024). The impact of cancer on mental health and the importance of supportive services: mental health and supportive services for patients with cancer. *Galen Medical Journal*, 13, e3327. DOI: https://doi.org/10.31661/gmj.v13i.3327
- Fernando A. (2020). Mental health and cancer: Why it is time to innovate and integrate-a call to action. *European urology focus*, 6(6), 1165–1167. DOI: https://doi.org/10.1016/j.euf.2020.06.025.
- Jevne, R.F., Nikolaichuk, C.L., & Williamson F.H.A. (1998) A Model for Counselling Cancer Patients. *Canadian Journal of Counselling*. 32(3), 213-229.
- Gibbons, S. W., Ross, A., Wehrlen, L., Klagholz, S., & Bevans, M. (2019). Enhancing the cancer caregiving experience: Building resilience through role adjustment and mutuality. *European Journal of Oncology Nursing*, 43, 101663. DOI: https://doi.org/10.1016/j.ejon.2019.09.004
- Guzzinati, S., Virdone, S., De Angelis, R., Panato, C., Buzzoni, C., Capocaccia, R., ... Dal Maso, L. (2018). Characteristics of People Living in Italy after a Cancer Diagnosis in 2010 and Projections to 2020. *BMC Cancer* 2018, 18:169. DOI:10.1186/s128850184053y
- Herrmann, C., Cerny, T., Savidan, A., Vounatsou, P., Konzelmann, I., Bouchardy, C., ... Ess, S. (2013). Cancer Survivors in Switzerland: A Rapidly Growing Population to Care for. *BMC Cancer* 2013, 13:287. DOI:10.1186/1471240713287
- Hu, Y., Liu, T. & Li, F. Association between dyadic interventions and outcomes in cancer patients: a meta-analysis. *Support Care Cancer*, 27, 745–761 (2019). DOI: https://doi.org/10.1007/s00520-018-4556-8
- IARC (2023). *IARC Biennial Report 2022–2023*. Lyon, France: International Agency for Research on Cancer. Retrieved from: https://publications.iarc.who.int/633. retrieved on November 23, 2024

- Jeffree, S. M., Mihat, O., Lukman, K. A., Ibrahim, M. Y., Kamaludin, F., Hassan, M. R., Kaur, N., & Myint, T. (2016). Surveillance Evaluation of the National Cancer Registry in Sabah, Malaysia. *Asian Pacific journal of cancer prevention*, 17(7), 3123–3129.
- Lim, G. C. C. (2002). Overview of cancer in Malaysia. *Japanese Journal of Clinical Oncology*, 32(1), 37–42. DOI: doi.org/10.1093/jjco/hye132.
- Mak, A. K., Chaidaron, S., Fan, G. & Thalib, F. (2014). Unintended Consequences: The Social Context of Cancer Survivors and Work. *Journal of Cancer Survivorship* 8, 269-281. DOI:10.1007/s1176401303306
- Marieke, V. D. W., Inge, V. O., Schouten, J., Thewes, B., Gielissen, M. & Prins, J. (2016). Fear of Cancer Recurrence in Prostate Cancer Survivors. *Acta Oncologica*, 55(7), 821-827. DOI:10.3109/0284186X.2016.1150607
- Miller, L. E. (2012). Sources of Uncertainty in Cancer Survivorship. *Journal of Cancer Survivorship*, 6, 431-440. DOI:10.1007/s1176401202297
- Morris, S.M. (2001). Joint and individual interviewing in the context of cancer. *Qualitative Health Research*, 11(4), 553-567.
- National Cancer Registry Department. (2023). *Summary of Malaysia National Cancer Registry Report 2017-2021*. Institut Kanser Negara, Ministry of Health Malaysia. [https://nci.moh.gov.my/images/pdf\\_folder/SUMMARY-OF-MALAYSIA-NATIONAL-CANCER-REGISTRY-REPORT-2017-2021.pdf](https://nci.moh.gov.my/images/pdf_folder/SUMMARY-OF-MALAYSIA-NATIONAL-CANCER-REGISTRY-REPORT-2017-2021.pdf) retrieved on November 24, 2025
- Ng, C. G., Mohamed, S., See, M. H., Harun, F., Dahlui, M., Sulaiman, A. H., Zainal, N. Z., ...on behalf of the MyBCC Study Group. (2015). Anxiety, Depression, Perceived Social Support and Quality of Life in Malaysian Breast Cancer Patients: A 1-year Prospective Study. *Health and Quality of Life Outcomes*, 13, 205. DOI:10.1186/s12955.015.0401.7
- Nour Hanan Daniah MB, Ahmad Anwaar MS, Siti Soraya AR, & Zarini I, (2021). Life experiences and coping mechanisms among breast cancer patients in an urban Malaysian hospital : a qualitative study. *Medicine & Health*, 16 (2), 148-160.
- Sauer, C., Weis, J., Faller, H., Junne, F., Hönig, K., Bergelt, C., Hornemann, B., Stein, B., Teufel, M., Goerling, U., Erim, Y., Geiser, F., Niecke, A., Senf, B., Weber, D., & Maatouk, I. (2019). Impact of social support on psychosocial symptoms and quality of life in cancer patients: results of a multilevel model approach from a longitudinal multicenter study. *Acta oncologica (Stockholm, Sweden)*, 58(9), 1298–1306. DOI: <https://doi.org/10.1080/0284186X.2019.1631471>
- Setoyama, Y., Yamazaki, Y. & Namayama, K. (2011). Benefits of Peer Support in Online Japanese Breast Cancer Communities: Differences BetweenLurkers and Posters. *Journal of Medical Internet Research* 13 (4).
- Taib, N. A., Yip, C. H. & Low, W. Y. (2011). Recognising Symptoms of Breast Cancer as a Reason for Delayed Presentation in Asian Women – The Psycho-socio-cultural Model for Breast Symptom Appraisal: Opportunities for Intervention. *Asian Pacific Journal of Cancer Prevention*, 12, 1601-1608.
- Tan, F. L., Loh, S. Y., Su, T. T., Veloo, V. W. & Ng, L. L. (2012). Return to Work in Multi-ethnic Breast Cancer Survivors – A Qualitative Inquiry. *Asian Pacific Journal of Cancer Prevention*, 13, 5791-5797. DOI:10.7314/APJCP.2012.13.11.5791
- Tian, X., Jin, Y., Chen, H., Tang, L., & Jiménez-Herrera, M. F. (2021). The positive effect of social support on psychological distress among Chinese lung cancer patients: The mediating role of self-esteem. *Nursing Open*, 8(4), 1964–1972. DOI: <https://doi.org/10.1002/nop2.793>
- Vivien, Y. W. C., Er, A. C. & Noor, N. A. M. (2013). Chinese Culture and Cancer among Malaysian Chinese Cancer Survivors. *Asian Social Science*, 9 (14), 30-41. DOI:10.5539/ass.v9n14p30
- Voon, S. P., & Chan, S. L. (2021). Counselling Cancer Patients: A Case Study of Perspectives of Professional Counsellors and Cancer Patients in Malaysia. *International Journal of Academic Research in Business and Social Sciences*, 11(17), 152–165.
- Wang, Y., Bao, S., & Chen, Y. (2023) How does social media use influence the mental health of pancreatic cancer patients: a chain mediating effect of online social support and psychological resilience. *Frontiers in Public Health* 11:1166776. DOI: 10.3389/fpubh.2023.1166776
- World Health Organization. (2024, February 1). *Global cancer burden growing amidst mounting need for services*. <https://www.who.int/news/item/01-02-2024-global-cancer-burden-growing-amidst-mounting-need-for-services>. Retrieved on March 6, 2025
- Williams, F. and Jeanetta, S. C. (2015). Lived Experiences of Breast Cancer Survivors after Diagnosis, Treatment and Beyond: Qualitative Study. *Health Expectations*, 19, 631-642. DOI:10.1111/hex.12372
- Yusuf, A., Hadi, I. S. A., Mahamood, Z., Ahmad, Z. & Keng, S. L. (2013a). Understanding the Breast Cancer Experience: A Qualitative Study of Malaysian Women. *Asian Pacific Journal of Cancer Prevention*, 14, 3689-3698. DOI:10.7314/APJCP.2013.14.6.3689
- Yusuf, A., Hadi, I. S. A., Mahamood, Z., Ahmad, Z. & Keng, S. L. (2013b). Quality of Life in Malay and Chinese Women Newly Diagnosed with Breast Cancer in Kelantan, Malaysia. *Asian Pacific Journal of Cancer Prevention*, 14, 435-440. DOI:10.7314/APJCP.2013.14.1.435
- Zade, H. A., Habibi, L., Arabtani, T. R., Sarani, E. M. & Farpour, H. R. (2017). Functions of Social Networks in a Community of Cancer Patients: The Case of Instagram, *International Journal of Networks and Communications*, 7(4), 71-78. DOI: 10.5923/j.ijnc.20170704.01.
- Zainal, N. Z., Nik-Jaafar, N, R, Baharudin, A., Sabki, Z. A. & Ng, C G. (2013). Prevalence of Depression in Breast Cancer Survivors: A Systematic Review of Observational Studies. *Asian Pacific Journal of Cancer Prevention*, 14, 3397-3404. DOI:10.7314/APJCP.2013.14.4.3397