

**MEANING IN LIFE AND HOPE AMONG YOUNG  
ADULTS WITH CANCER IN MALAYSIA**

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# **MEANING IN LIFE AND HOPE AMONG YOUNG ADULTS WITH CANCER IN MALAYSIA**

by

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## **LIST OF ABBREVIATIONS**

AYAs	Adolescents and Young Adults
GLOBOCAN	The Global Cancer Observatory
HCP	Healthcare Professional
MIL	Meaning in life
UNICEF	United Nations Children's Fund

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# **MAKNA DALAM KEHIDUPAN DAN HARAPAN DALAM KALANGAN DEWASA MUDA YANG MENGHIDAP KANSER DI MALAYSIA**

## **ABSTRAK**

Mempunyai rasa makna dan harapan telah dikaitkan dengan kesihatan yang lebih baik, kualiti hidup dan fungsi harian. Walau bagaimanapun, mencari makna dan mengekalkan harapan berikutan diagnosis kanser boleh menjadi sukar, terutamanya bagi orang dewasa muda yang menghidap kanser. Tujuan kajian ini adalah untuk mengkaji bagaimana golongan dewasa muda yang menghidap kanser mencari makna dan harapan dan bagaimana kedua-dua elemen ini mempengaruhi perjalanan kanser mereka. Kajian kualitatif ini menggunakan pendekatan fenomenologi, yang melibatkan penyertaan empat belas orang dewasa muda yang didiagnosis dengan kanser yang direkrut daripada kumpulan Facebook tertutup. Orang dewasa muda ini berumur antara 20 hingga 39 tahun, dan tahun kelangsungan hidup mereka adalah antara 1 hingga 18 tahun. Temu bual separa berstruktur dan analisis tematik telah dilakukan untuk mengenal pasti tema utama yang muncul daripada temu bual ini. Hasil kajian mendapati bahawa majoriti golongan muda yang menghidap kanser dalam populasi ini mendapati makna positif dalam penyakit mereka, dan mereka melihat penyakit kanser dari perspektif agama. Agama berfungsi sebagai sumber ketenangan, dan ia memberikan mereka kekuatan dalaman semasa penderitaan. Orang dewasa muda menyatakan harapan untuk membantu pesakit kanser, kesihatan fizikal dan mental yang baik, dan kemudahan di akhirat. Kepercayaan budaya dan agama mereka menentukan pelbagai bentuk harapan dan seterusnya, bagaimana harapan mempengaruhi pengalaman mereka dengan kanser. Kajian ini mendapati bahawa tidak semua komunikasi positif dengan doktor menghasilkan harapan. Golongan dewasa muda juga menekankan bahawa

mempunyai matlamat dan berusaha untuk mencapainya walaupun menghidap kanser dianggap penting. Penemuan ini memberikan pemahaman kepada profesional penjagaan kesihatan dengan menggalakkan golongan dewasa muda meneroka makna dalam kehidupan, mencari harapan dan menambah baik campur tangan berasaskan kerja sosial sedia ada. Kajian ini mencadangkan bahawa makna dalam kehidupan dan harapan adalah perbincangan penting untuk pesakit yang menghidap penyakit kronik dan harus disokong secara berterusan sepanjang dan selepas rawatan.

# **MEANING IN LIFE AND HOPE AMONG YOUNG ADULTS WITH CANCER IN MALAYSIA**

## **ABSTRACT**

Having a sense of meaning and hope has been linked to better health, quality of life, and daily functioning. However, seeking meaning and preserving hope following a cancer diagnosis can be difficult, particularly for young adults with cancer. The purpose of this study was to investigate how young adults with cancer sought meaning and hope and how these two elements influenced their cancer journey. This qualitative study employed a phenomenological approach, which involved the participation of fourteen young adults diagnosed with cancer that recruited from a closed Facebook group. These young adults ranged from 20 to 39 years in age, and their survival years ranged from 1 to 18 years. Semi-structured interviews and a thematic analysis were performed to identify the major themes that emerged from these interviews. The findings revealed that the majority of young people with cancer in this population found positive meaning in their illness, and they perceived cancer from a religious perspective. Religion served as a source of comfort, and it provided them with inner strength during times of suffering. Young adults expressed hopes for helping cancer patients, good physical and mental health, and an ease in afterlife. Their cultural and religious beliefs determined the various forms of hope and subsequently, how hope affected their experiences with cancer. This study observed that not all positive communication with physicians resulted in hope. The young adults also highlighted that having goals and striving to achieve them despite having cancer was considered essential. These findings provided valuable understanding to healthcare professionals (HCPs) by encouraging young adults to explore meaning in life, seek hope, and improve the existing

social work-based intervention. This study suggests that meaning in life and hope are important discussions for patients with chronic illness and should be continuously supported throughout and after treatments.



## **CHAPTER 1**

### **INTRODUCTION**

#### **1.1 Research Background**

Cancer is a worldwide burden as it is the leading cause of death worldwide. In 2018, it was estimated that there were 18.1 million new cancer cases and 9.6 million cancer deaths worldwide, with a 20 percent risk of developing cancer before the age of 75 and a 10 percent risk of dying from it (Ferlay et al., 2018). According to the most recent data from The Global Cancer Observatory (GLOBOCAN) for 2020, there will be approximately 19.3 million new cancer diagnoses and 10 million cancer-related deaths in 2020 (Sung et al., 2021). In 2040, it was expected that there would be 28.4 million new cases of cancer, a 47 percent increase from the equivalent 19.3 million cases in 2020 if national rates remained constant in 2020 (Sung et al., 2021).

Cancer remained a leading cause of premature death in Malaysia (National Cancer Institute, 2019). In 2020, Malaysia recorded 48,639 new cases, and the number of deaths was 29,530 (GLOBOCAN, 2020). The illness has had a tremendous impact on the community and health care system and increased the burden on the Malaysian government. According to the latest Malaysia National Cancer Registry Report 2012–2016 (MNCRR), there were 103507 cancer cases in 2012, and the cases increased to 115238 cases in 2016. Lymphoma is a common type of cancer that affects children and young adults of both sexes. While colorectal cancer was the most common disease in men aged 25 and older, breast cancer was the most common cancer diagnosed in women aged 25–59 in Malaysia (MNCRR, 2012–2016).

Having cancer at a young age can be traumatic. Young adulthood is a critical period where young people approach adulthood since it is a transitional phase in which

individuals usually attend high school or university, begin their career involvement, engage in relationships, and have children. The United Nations Children's Fund (UNICEF) defined young people as those aged 10 to 24. This definition, however, changes according to country and policy. In the context of cancer, young adult cancer patients were formally defined as groupings of adolescents and young adults (AYA) aged 15–39 years, as the term was widely used (Adolescent and Young Adult Oncology Progress Review Group, 2014; Bleyer & Barr, 2009). This is an important stage in life in which a person starts to search for meaning in life (MIL) and hope in their future life (Rathi & Rastogi, 2007; Schippers & Ziegler, 2019). MIL is a process of discovering meaning and purpose in one's life, and it is the primary motivational force in humanity (Victor Frankl, 1959). It was a valuable tool for imposing stability on every phase of life (Baumeister et al., 2013) to have positive experiences, an appreciation of life, and healthy self-esteem (Evan & Zeltzer, 2006; Abeyta et al., 2015; Schlegel et al., 2011).

However, young adult's patients reported experiencing extreme shock and stress following a cancer diagnosis (Ginter, 2020). They expressed their current life as being shattered by the fact that they had cancer, which presented them with challenges in confronting reality (Hauken et al., 2013). Young adults' patients find it hard to find their MIL after receiving a cancer diagnosis. Despite this, studies have shown that people will seek out MIL even when they are ill (Frankl, 1959; Büssing et al., 2005; Jim et al., 2006). The situation can be made more complicated by the fact that young adults experience a period of transition between adolescence and adulthood (Bleyer, 2007) and developmental needs (D'Agostino et al., 2011). Their illnesses, development, and needs can make it challenging for them to discover meaning in their lives (Heintzelman et al., 2013). Nonetheless, it was crucial for young adults to have a sense

of meaning and purpose in life, as it increased their life satisfaction and psychological well-being as they explored ambitious goals (Krok, 2018; Schippers & Ziegler, 2019; Steger et al., 2009).

Meaning in life is unique and varies according to personal circumstances. Nevertheless, individuals would search for meaning despite hardship (Büssing et al., 2005; Frankl, 1959; Tomás-Sábado et al., 2015). In the context of cancer patients, young adults were determined to search for meaning (Tomás-Sábado et al., 2015). They will have deep thoughts to reflect on their lives and what cancer means to them as they progress (Jones et al., 2011). Having meaning in life helps young adults to cope with disappointment during the cancer experience and promote their mental resilience (Park et al., 2010). The presence of meaning might avoid intrusive thought (Park et al., 2010) which leads to enhanced well-being, minimizing levels of psychological discomfort among young adults (Vickberg et al., 2000). In contrast, the inability to find meaning in their lives can lead to struggles in coping with their current situations or the negative outcome (Marcus, 2012; Marshall et al., 2019).

Folkman (2010) argued that hope can be an effective coping mechanism for cancer patients to maintain a sense of control, discovered sense of purpose, and hope for a new goal in order to adapt to the illness. Hope was described as a coping mechanism that aids cancer patients in adjusting to treatment sessions, coping with an uncertain prognosis, and psychologically adjusting (Cheavens et al., 2005; Clayton et al., 2005). However, maintaining hope after a cancer diagnosis can be challenging. This situation may be more difficult for young adult's patients if they lack of experience and preparation to develop coping strategies while dealing with their illness (Kok, 2015; Aderhold et al., 2019; Hauken, 2013). It was a traumatic experience to deal with cancer during crucial developmental stages (Zebrack & Chesler, 2001). Low levels of hope

and depression and distress were found to have a significant relationship with the inability to cope among young people with cancer (Niedzwiedz et al., 2019; Rosenberg et al., 2018; Zhang, 2021).

Furthermore, when individuals are confronted with difficulties, such as a chronic or life-threatening illness, many tend to respond with hope (Hsu et al., 2006). Individuals who have high levels of hope are more likely to use coping methods such as positive reappraisal and believe their coping efforts matter in fighting cancer (Berenides et al., 2010). Younger cancer patients are more committed to combat cancer and favor hope over resignation as a coping method (Hernandez et al., 2019). As a result, young adults with cancer are more appreciative of their current and future accomplishments.

Even though MIL and hope were important for young adults with cancer, there were few studies from a social work perspective in Asian settings (Chan, 2017; Mahendran et al., 2016). There was a lack of understanding regarding MIL among young adults and the influence of hope among young adults with cancer. Therefore, the purpose of this study is to examine what cancer means to them and how young adults seek hope. This study will contribute to the improvement of existing social work-based interventions in oncology settings by incorporating MIL understanding and hope among young adults with cancer.

## **1.2 Problem Statement**

Cancer among young adult has imposed a significant societal and economic burden owing to the significant consequences of premature morbidity and mortality (Fidler et al., 2017; Veettil et al., 2017). Many play a significant role in caring for their

young families. Moreover, young adults were important as they have a substantial proportion of their expected lifespans remaining and have much potential to contribute to the economy. Though there were alarming cancer cases among young adults (Coccia, 2019; Drake & Urquhart, 2020), this topic is scarcely discussed due to a lack of statistics, especially in Malaysia (Zainab Chaudhry et al., 2016; Abdul-Razak et al., 2017).

In addition, most studies of MIL were limited to older adults, palliative care, and the end-of-life experience context (Clayton et al., 2008; Karlsson et al., 2014; Tomás-Sábado et al., 2015; Zumstein-Shaha et al., 2020). There was a limited understanding of how young adults find MIL after the diagnosis, especially when they must cope with the situation in which they were torn between a successful treatment or not.

Moreover, despite the unpredictability of cancer, hope was referred as a factor in successful recoveries and goal-directed behaviour (Ginter, 2020; Hauken et al., 2019; Park et al., 2008). However, there was lack of exploration on the hope in young adult with cancer, particularly in the context of an uncertain future following the diagnosis. The elements of hope that emerged and intertwined following a cancer diagnosis were complex and warranted additional study (McInally et al., 2021). Hope in young adults with cancer should be studied in a separate age group based on the severity of their cancer and their age (Nierop-van Baalen et al., 2020). Research suggested that young adult cancer patients are more likely to face more challenges due to their diagnosis because most lack the experience and maturity to develop healthy coping techniques when faced with adverse situations (Aderhold et al., 2019). Often, restoring hope after traumatic or adverse events might be challenging, particularly for a young adult who is diagnosed with cancer.

There are several psychological factors linked to hope. Some young people in cancer may have lost confidence in themselves because of living with cancer during an important developmental stage (Zebrack & Chesler, 2001). Depression is significantly associated with a low degree of hope (Niedzwiedz et al., 2019; Zhang, 2022). Even though some adolescents with cancer may perceive their current lives as worse than those of their healthy peers, they appear to have higher levels of hope, experience less disturbance, and fewer memory issues (Tremolada et al., 2020). This suggests that hope could be a source of mental sustenance throughout one's cancer treatment and a guiding source of motivation following treatment for young adults with cancer (Bennett et al., 2022). Given the lack of studies on MIL and hope, limited studies used qualitative methods to understand these topics. Wayant et al. (2021) noted that most observational and mixed-methods research in hope and MIL was less focused on young cancer patient interviews and very few was focused on interventions. Previous studies were unable to fully comprehend the MIL process due to a rigid definition of MIL. Most recent studies in Malaysia have focused on varying ages and used a quantitative approach to measure hope and MIL (Abdullah et al., 2018; Pahlevan Sharif et al., 2021). Darabos and Ford (2020) argued that there were multiple definitions of MIL based on their various experiences throughout their cancer-battling journey. In the quantitative literature, the unique characteristics of how they define their current and future lives in cancer illness were frequently overlooked (Darabos & Ford, 2020).

In addition, many existing studies were conducted in a Western context, with the majority of them examining the influence of chaplains, religion, and spirituality on MIL and hope (Barton et al., 2018; Proserpio et al., 2020). The study by Abdullah et al. (2018) did not explain MIL and hope in the context of cancer from a cultural standpoint in Malaysia. This will differ depending on the country and may be irrelevant to

some cultures. The societal values of Westerners and Asians can differ and should be studied further from a cultural standpoint. As Malaysia is a multi-religious country and collectivistic in culture (Oka et al., 2017), studies noted that it is necessary to consider cultural strengths as motivational sources and resources in supporting hope (Edwards & McClintock, 2018).

Furthermore, medical social workers were among the trained professionals who played a significant role in assisting young cancer patients (AOSW, 2017). Medical social workers work closely with cancer patients to help them cope with their mental health issues. Their responsibilities include assisting cancer patients in coping with the illness and finding meaning in their lives. MIL identification was critical to assisting young adults in coping with the crisis and moving on with their lives (Park et al., 2010). However, Yusof et al. (2019) reported a lack of healthcare social workers in Malaysian mental health settings. There was a lack of information on how medical social workers assist cancer patients, particularly young adults with cancer, in balancing their journey to find MIL while preserving their future hopes (Boddy et al., 2018; Guthrie et al., 2014; Itzhaky & Lipschitz-Elhawi, 2004). A lack of professional support, particularly among medical social workers, may increase the risk of cancer patients developing mental health issues.

The purpose of this exploratory study is to understand the experiences of young adults with cancer and to investigate how MIL and hope affect young adults with cancer throughout their cancer journey. This study would be beneficial in evaluating the role of social workers in filling gaps in the health sector, government departments, and human services.

### **1.3 Research Questions**

- i) What are the experiences of young adults with cancer throughout the cancer journey?
- ii) How does a young adult with cancer describe their meaning in life?
- iii) What are the hopes of young adults with cancer and how does hope influence experience of young adults?
- iv) How can social work integrate the elements of the explorations of meaning in life and hope into existing interventions for young adult with cancer?

### **1.4 Research Objectives**

- i) To explore the experiences of young adults with cancer throughout their cancer journey.
- ii) To explore meaning in life in young adults with cancer.
- iii) To explore hope and the influence of hope among young adults with cancer.
- iv) To improve the existing social work intervention by integrating elements of the explorations of meaning in life and hope in supporting young people with cancer.

### **1.5 Significance of Study**

This study is crucial in many areas, including adding to the literature on MIL and fostering hope among young adults with cancer. There is a lack of existing literature on the experiences of young adults with cancer, particularly in Malaysia. Moreover, age-specific data is not properly disaggregated in Malaysia (National



Cancer Institute, 2019). The most recent Malaysia National Cancer Registry Report (MNCR) categorises cancer by age into five broad age groups: 1) children under 14 years of age, 2) the 15–24-year age group categorised as children and adolescents, 3) the 25–59-year age group, 4) the 60–74-year age group, and 5) age 75 years and older (National Cancer Institute, 2019). As young adults are grouped with children and older individuals in national registries, young adult patients in Malaysia seemed to have been ignored or dismissed. Sabri et al. (2023) noted that lack of focus on young adults with cancer in Malaysia has led to a deficiency in support groups tailored to this demographic. Consequently, young adults with cancer may face challenges in sharing their experiences and receiving emotional support from peers of the same age group (Sabri et al., 2023).

MIL and hope were found to be important protective factors in chronic illness and to be associated with improved health (Park et al., 2010; Brassai et al., 2011; Griggs & Walker, 2016). Having MIL helps young individuals cope with frustrations encountered during their cancer journey and improves emotional resilience (Park et al., 2010). Young adults who successfully acquired meaning were able to use active coping strategies and adaptive outcomes to alter the meaning of stressful situations, making them less threatening and more positive (Trask et al. 2003). In this way, they were able to understand the significance of life, including the acceptance of cancer (Park, 2010). Young adults who are unable to find meaning, on the other hand, may be prone to life disturbances, resulting in anxiety and despair because of a cancer diagnosis (Zebrack and Chesler, 2001).

Furthermore, hope is a critical issue to address amongst young adults facing chronic illness because it allows one to maintain a sense of control and purpose while optimistically anticipating something positive for their future goals (Folkman, 2010).

A person who has hope is more likely to overcome difficult events and has higher subjective wellbeing (Yıldırım, 2022). On the contrary, individuals who lack hope are more prone to experiences of psychological discomfort such as worry and sadness. Therefore, understanding life experiences of young adults with cancer could help them explore and balance their current situation and a positive future (Schmid & J. Lopez, 2011; Gray et al., 2018).

Engagement with young adult patients necessitated the formal support of healthcare professionals. Young adult with cancer required hope interventions because they received inadequate support in developing hope (Shin and Oh, 2021). The hope intervention required greater collaboration from all healthcare professionals (HCPs) in order to engage with young adults (Thompson et al., 2013; Berger et al., 2019). To address the uniqueness of young adult, HCPs must have a specific set of skills, formal knowledge, and attitude (Haugan, 2013; Pearce et al., 2018). This study added to the existing body of knowledge about the importance of professional responsibilities in assisting young cancer adult in their search for MIL and hope. It emphasized the importance of understanding cancer in young adults and raising awareness among academics, practitioners, and policymakers.

In addition, this study provided an opportunity for social workers as health care professionals to have a better understanding of the unique obstacles faced by young cancer patients and to assist them in developing the necessary coping skills. It highlighted the significance of providing an adequate support system and enhancing professional assistance to enable cancer patients to find MIL and hope during their journey. In addition, when treating and caring for young cancer patients, social difficulties and developmental needs must be acknowledged and comprehended (Docherty et al., 2015; Tsangaris et al., 2014). This could help enhance the social work principles of

social workers. Given this, social workers may find it advantageous to re-evaluate how they offer services, particularly in the field of psychosocial oncology, which would be of tremendous importance in expanding social work literature. In other words, this study will contribute to the validation of the social work profession in caring for young adults with cancer.

The meaning of "hope" and "MIL" differs by culture. Research has suggested that in an American sample, whose culture emphasizes individuality, individual decisions resulted in the highest amount of motivation, with decisions made by closed groups placing second (Deci & Ryan, 2000). In the Asian sample, where collectivism is valued, people who accepted the decision made by a trusted and closed group had the highest levels of motivation, whereas those who made independent decisions had the lowest (Deci & Ryan 2000). As Malaysia is a multireligious country and collectivistic in culture, with Asian backgrounds, studying hope among young adults with cancer would contribute significantly to how aspects of religion and culture play a role in sustaining hope and MIL. It was essential for social workers to understand in Malaysian context in order to help young adults with cancer construct meaning and develop hope during their cancer experience. This study was valuable to the qualitative area because it identified potential features that may be absent or overlooked in quantitative research.

This study indicated that the distribution of cancer in young adults was unique. It motivated and assisted young cancer patients who had lost meaning and hope in life. Understanding the experiences of young people with cancer from a social work perspective contributed to social work interventions to support young people with cancer.

## **1.6 Scope of Study**

The study utilizes a qualitative phenomenological approach to understand the experience of young adults with cancer in Malaysia throughout their cancer journey. This study aimed to explore themes of hope and meaning in life among young adults with cancer, in addition to improving the existing social work intervention in supporting these young adults. The research is limited to participants within the specified age range, 15 to 39 years old. The research aims to provide insights into the experiences of young adults with cancer and contribute to the existing literature on hope and meaning in life among young adults in Malaysia. The study does not delve into medical treatment outcomes or specific medical interventions. The findings will be valuable for healthcare professionals, researchers, and policymakers involved in the care and support of young adults with cancer.

## **1.7 Conceptual definitions**

**Young adults with cancer.** Conceptual definition: Young adult cancer patients were formally defined as groupings of adolescents and young adults (AYA) aged 15 to 39 years as the term was widely used (Adolescent and Young Adult Oncology Progress Review Group, 2014; Bleyer & Barr, 2009).

**Hope.** Conceptual definition: Hope was defined as positive emotional states that emphasize cognitive factors about goal-related behavior, the agency component captures a sense of personal energy and pathway components that demonstrate to determine to meet goals (Snyder et al., 1989). It provided comfort while enduring life threats. In the context of illness, hope was reported to be important for effective cop-

ing, decision making, psychosocial adjustment, quality of life, and even for the promotion of healing for cancer patients (Collins, 2015; DeMartini et al., 2019; M. Y. Li et al., 2016; Rock et al., 2014).

**Meaning in life (MIL).** Conceptual definition: MIL was defined by Steger (2009) as the degree to which a person understands their life, thinks it is important and meaningful, and thinks they have a goal or purpose in life. MIL relates to improved stress management, and individuals tend to employ appropriate coping mechanisms. It provided individuals with a sense of purpose and drive in their lives (Schnell, 2009).

**Goal(s).** Conceptual definition: Goals were the target of mental action sequences (Snyder, 2000). Individuals would assume an outcome because of their actions or performance (Locke et al., 1981). Goals can be diverse and include the five fundamental needs identified by human motivation theory.

## **1.8 Summary and conclusion**

In conclusion, this study provided some insight into the specific issues that young adults with cancer experience, stressing the significance of adding meaning in life and hope into social work interventions. The examination of their experiences throughout the cancer journey has provided vital insights on dealing with cancer. The findings emphasize the need of understanding the meaning that young adults with cancer assign to their life, as well as the critical role that hope plays in shaping their entire experience. This study not only contributed to the existing gaps in social work perspectives in Asian settings, but it also provided a platform for improving treatments in cancer settings. This knowledge not only broadened awareness of the difficulties encountered by young adults with cancer, but it also offered more specialised recommendations that have the potential to significantly improve their quality of life.

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

This chapter aimed to provide explanations of hope and meaning in life from previous literature and theories. This chapter also included discussions on previous studies on young adult with cancer and the challenges, meaning in life, hope, and support systems that the young adult received throughout the cancer journey. At the end of this section, a conceptual framework was shown. This framework was used as a guide for this research.

#### **2.2 Young people with cancer**

Numerous studies found that four behavioural risk factors — tobacco use, a poor diet, physical inactivity, and harmful alcohol use were significant cancer risk factors in Malaysia (Lim, 2002; Teh & Woon, 2021; Wong et al., 2016). A recent study in the United States found that the incidence of cancer among adolescents and young adults increased by 29.6 percent, from 57.2 percent to 74.2 percent of invasive cancer diagnoses per 100 000 adolescents and young adults each year (Scott et al., 2020). Scott et al. (2020) identified environmental factors, dietary and obesity trends, and changes in screening procedures as three significant contributors to the increase in the cancer rate among young people between 1973 and 2015. Tan et al. (2020) found in a recent study that alcohol consumption contributed the least to total cancer in Malaysia compared to other countries. This may be due to cultural factors, as the majority of Malaysia's population is Muslim and alcohol consumption is prohibited by Islamic doctrine (Tan et al., 2020). However, it could be argued that younger Malaysians were

increasingly exposed to urbanisation and modern lifestyles, both of which are significant behavioural cancer risk factors (Jan Mohamed et al., 2015).

According to the National Strategic Plan for Cancer Control Program, Malaysia aimed to reduce cancer incidence and mortality as well as improve the quality of life for cancer patients with advanced disease through access to pain relief and palliative care (Ministry of Health Malaysia, 2017). Abdul-Razak et al. (2017) argued that such measures should make equity accessible to all, including young individuals. This was related to the fact that young adults with cancer who have recently completed treatment and were coping with residual treatment effects may experience high anxiety levels (Arpawong et al., 2013). In this case, young adults with cancer were burdened by ambiguity, which could hinder their development and necessitate further research.

### **2.3 Young adult in a care setting**

Bleyer (2009) emphasised the invulnerability of young adults because cancer was typically associated with older people. Clinicians have a low suspicion of cancer in this age group, whereas young adults believed they were "not supposed" to develop cancer (Adolescent and Young Adult Oncology Progress Review Group, 2006). According to Haase and Phillips (2004), adolescents and young adults were "invisible" in cancer care for three major reasons: 1) Research reports that fail to differentiate adolescent and young adult data from that of children or adults; 2) adolescents and young adults receiving care in settings not designed to meet their specific needs; and 3) a possible conceptual misunderstanding by health care providers of adolescent and young adult treatment commitment. Even though young adults had a lower incidence of cancer than older adults, the remaining substantial proportions of lifespans contributed significantly to the economy and played a vital role in caring for their families.

There was no clear definition of a paediatric setting or general ward in Malaysia (The Star, 2012). According to the Medical Development Division of the Ministry of Health (2012), 16- to 18-year-old patients who need continuous medical care should be prepared for transfer to adult services. Young adult patients complained that the physical environment for treatment was inappropriate for their age, such as when they were treated in children's hospitals or facilities for adults with many older patients (Zebrack and Isaacson, 2012).

## **2.4 The implications of cancer to young people.**

### **2.4.1 Financial toxicity and employment of young people with cancer**

Living with long-term treatment can be costly, especially for cancer patients from low-income families. Financial toxicity refers to the financial burden associated with cancer due to out-of-pocket expenses. It has direct and indirect effects on healthcare expenditures (Zafar & Abernethy, 2013). Financial toxicity not only manifested itself monetarily, but also led to increased psychosocial distress, adverse patient outcomes, and diminished quality of life (Zafar & Abernethy, 2013). A Malaysian study also found a correlation between financial toxicity and the age, household income, and educational level of survivors (Yap et al., 2020). Throughout their cancer journey, Yap et al. (2020) found that younger cancer survivors in Malaysia were more likely to experience financial hardship than older patients.

In addition, Richman & Brodie (2014) found that younger adults have fewer savings or more expenses, making it more difficult to pay for medical expenses. Richman & Brodie (2014) explained that older people, such as retired adults, typically have a greater number of assets, such as home ownership, pensions, and retirement plans, as income and security sources. A study conducted in Malaysia revealed that some



households of cancer patients borrowed money and sold their homes to pay for medical care, while others relied on their current income and savings to counter the threat to their financial stability (Azzani et al., 2017).

As a result of their cancer treatment, cancer patients faced substantial cost-sharing increases (Yousuf Zafar, 2016). One of the reasons why young cancer patients avoided treatment was that it would require them to miss work and reduce their income, making it difficult to pay their bills (Zebrack & Isaacson, 2012). In addition, the financial burden of cancer care affects a patient's finances and mental health, resulting in delayed diagnosis and treatment (Whitney et al., 2016). Kielb et al. (2017) emphasised that these circumstances are a significant public health concern because they result in inadequate treatment of chronic health conditions, increase the likelihood of health issues going undiagnosed, and likely increase potential health care costs by failing to prevent more severe health conditions.

Keegan et al. (2012) also discovered that working-age survivors and young people just starting out in the workforce were vulnerable to financial burdens. Yabroff et al. (2015) emphasised that they have limited access to insurance, which, when combined with lower earnings, may increase the risk of material and psychological financial hardship. Even though some young people had insurance, Richman and Brodie (2014) argued that it may not be sufficient to protect them from substantial costs. It was important to take into consideration regarding their medical expenses, income, investments, and other resources (Richman & Brodie, 2014). Banegas et al. (2016) discovered that working young adults have more financial obligations than older adults, thus they were more likely to incur debt and declare bankruptcy. Overholser et al. (2017) suggested that young adults must acquire new skills in order to navigate the healthcare system and obtain and maintain health insurance coverage.

Daher (2012) claimed that there was a prevalent assumption that a person who has been diagnosed with cancer is too ill to be employed. Guy et al. (2014) emphasized that young cancer survivors were more likely to report being unable to work, missing more days of work due to illness or injury, and spending more time in bed because of their health than adults who had never had cancer. Even if a cancer patient has a job, young adults are at a disadvantage when it comes to salary or promotion (Bae and Cho, 2021). Due to these negative perceptions, cancer has frequently been hidden in the workplace and among co-workers (Daher, 2012; Bae & Cho, 2021).

#### **2.4.2 Negative Self-image and romantic relationship**

Young people were exploring their sexuality, love relationships, and psycho-sexual identities (Tolman & McClelland, 2011). These three crucial elements were interrelated. According to Cherven et al. (2021), survivors' romantic relationships may suffer as a result of poor body image, and sexual dysfunction, including lack of desire, may be influenced by body image, causing stress in romantic relationships. Veneroni et al. (2020) emphasized the importance of preventing disease from interfering this developmental process, which has biological, psychological, and social implications.

In addition, adolescents frequently expressed concerns about their appearance, self-perception, and body image, especially body image (Ettinger & Heiney, 1993). Conarpentier et al. (2011) discovered that surviving testicular cancer and experiencing hair loss made individuals feel unique and damaged. In addition, Olsson et al. (2018) emphasised that weight loss or gain, the loss of a body part, and scars negatively affect social and romantic interactions. According to Evan et al. (2006), adolescents with cancer were hesitant to disclose their cancer diagnosis or any physical flaws to romantic partners.

In addition, Zucchetti et al. (2017) determined that the body image of female survivors was more impaired and significantly different than that of male survivors. Females exhibited greater concerns regarding weight gain and physical appearance than males (Zucchetti et al., 2017). According to Hassan et al. (2015), unmarried women were more depressed than married women because they feared losing their partner and friends as a result of a decline in feminine attractiveness. This demonstrated that for young people with cancer, dating and disclosure become uncertain, and these uncertainties may leave young people with cancer feeling deprived of fulfilling companionship and ultimately alone (Zebrack & Isaacson, 2012).

According to Mohd-Sidik et al. (2018), changes in their body image have lowered their self-esteem. This could be described as "identity loss," which referred to the inability to relate to others due to physical changes (Tindle, Denver, & Lilley, 2009). Brierley et al. (2019) supported the notion that adolescents and young adults with cancer have a fundamental need to feel the same as their peers, given that at this age they are discovering their own and others' bodies. Therefore, it was not surprising that many adolescents and young adults with cancer expressed a desire to regain their previous appearance and lifestyle (Brierley et al., 2019).

### **2.4.3 Infertility in young people with cancer**

Fertility was a crucial factor for young adults who planned to start or expand their families in the future (Zebrack et al., 2004). According to Shnorhavorian et al. (2015), there was uncertainty surrounding the low-to-impossible likelihood of certain young people having biological children due to infertility issues resulting from cancer treatments. However, according to a study by Gorman et al. (2012), the majority of women in both groups chose to proceed with the recommended treatment and accept

the possibility of infertility because survival was the most important factor for them and their families.

Wettergren et al. (2017) found that young breast cancer survivors without children were more likely to report negative effects on sexual function and intimate relationships. According to Wettergren et al. (2017), one of the possible reasons was the fear that the cancer treatment would prevent them from having children. This fear made sexual activity difficult or even ended the relationships. Nahata et al. (2020) also reported that women were more likely to express a lack of physiological understanding and to feel pressured to create permanent relationships and disclose to partners in a timely manner so as not to jeopardise their chances of motherhood. Benedict et al. (2016) discovered that one woman brought in her ex-family boyfriend, who demanded proof that she was capable of having children. This was a result of males emphasising the significance of reproduction and parenthood to their non-cancer partners. Even in people who had no intention of having children, the threat of infertility influenced a profound sense of loss and anger (Duffy et al., 2009).

At the same time, Reinmuth et al. (2008) highlighted that both men and women with cancer were worried about potential health issues for themselves, the safety of pregnancy, and the possible risks to their potential offspring. Schover (2005) says that only a small number of young adults have a known genetic mutation that increases their lifetime risk of cancer. However, the development of genetic testing for hereditary cancer syndromes has created new problems for people who want to have children. Despite this fear, Hawkey et al. (2021) revealed that the absence of discussion of fertility concerns was often reported to avoid this distressing issue. Therefore, fertility issues must be addressed with sensitivity and respect (Benedict et al., 2016).

## **2.5 Meaning in life in facing cancer**

Meaning is essential for living a purposeful life, even in the face of adversity (Frankl, 1963). The concept of purpose in life originates from Frankl's writings on the "will to meaning" as the basic motivator for survival. According to Haugan and Erikson (2021), people's perceived meaning in life is related to what they are committed to; one's unique contribution to a better world provides purpose and meaning. Meaning is discovered and determined by the individual's uniqueness and specific life situation (Frank, 1963).

According to Steger's (2009), MIL includes people's understanding of the meaning and purpose of their life. It reflects one's perception of life as meaningful and purposeful, along with a sense of direction towards specific goals or objectives (Martela & Steger, 2016). Additionally, MIL offers individuals a profound sense of purpose and motivation, driving them to pursue their aspirations and goals with determination and resilience (Schnell, 2009). This concept underscores the importance of understanding the existential significance of life experiences and the profound impact it can have on psychological well-being and resilience in the face of adversity (Kim et., al 2022).

Meaning in life is particularly important for people dealing with chronic illnesses like cancer. These conditions frequently elicit existential questions and reflections on life's purpose. According to Korkmaz and Güloğlu (2021), cognitive adjustment and coping with chronic illness require understanding and assigning meaning to its challenges. Recent research demonstrated that patients who experience meaning in life have better coping skills (Marco et al., 2023) and more likely to report acceptance

of cancer (Secinti et al., 2019; Quinto et., 2022). Cancer patients are able to make sense of their illness and perceived a less negative view (Park, 2010).

Studies also showed that meaning in life has several potential implications for improving health outcomes (Krok&Telka, 2018; Dezutter et al., 2015). It has been linked to improved psychological health, well-being, and quality of life for patients with chronic conditions (Dezutter et al., 2013; Hooker et al., 2018). Bernard et al. (2020) discussed that having meaning reduces depression and improves recovery from illness. Patients are less affected by daily stressors (Winger et al., 2016), have a greater ability to tolerate bodily discomfort despite pain (Marco et al., 2023), and reported a higher quality of life (Bernard et al., 2020; Haugan & Dezutter, 2021; Almeida et al., 2022). In contrast, people who lack meaning in their lives are more likely to have poor physical health and mental health issues (Ahab et al., 2019).

Furthermore, people give their lives meaning by establishing and pursuing goals that reflect their values (Feldman and Snyder, 2005). Meaning in life is unique to each person and varies based on developmental stage and personal circumstances. In general, young adults are moving toward independence and establishing long-term goals for meaningful lives. According to Steger et al. (2006), the development of life's meaning parallels the maturation of one's identity. Darabos and Ford (2020) found that some adolescents and young adults may or may not identify as "cancer survivors." Even though cancer impacted their lives, they reported not worrying excessively about it or allowing it to define their present existence. In contrast to Jones et al. (2011), the young cancer survivors in their study contemplated their lives and what cancer would mean as they grew older. Even though they were identified as cancer survivors, the fact that their cancer identity alternated with their survivor identity caused them to be uncertain about which group they belonged to (Jones et al., 2011). According to a 2013

study by Kumar and Schapira, young adults were uncomfortable with the term "survivor" because it implies too much sympathy from others. However, it could be argued that different individuals construct unique identities, but it is undeniable that this contributes to the formation of a variety of meanings.

According to Steger et al. (2009), individuals in later life stages experienced greater meaning than those in earlier life stages. Reker et al. (1987) compared MIL among young, middle-aged, and older adults and discovered that many young females indicate they have not yet discovered a fulfilling life purpose, whereas many elderly females claim to have. This is probably due to the fact that young adults have a strong desire to achieve new goals despite being exposed to a variety of life experiences in a short period of time, whereas older adults can reflect on their past and find meaning in what they have accomplished (Reker et al., 1987). Marcus emphasized that some high school students with cancer may still be unable to comprehend the significance and impact of their diagnosis. In addition, young cancer patients have endured a variety of obstacles, and many have expressed a need to find meaning in order to cope with their devastation (Park et al., 2010). Barakat et al. (2016) found that adolescents and young adults with cancer who lacked a sense of meaning or purpose perceived themselves as less resilient. In contrast to Zamora et al. (2017), adult survivors of childhood and adolescent cancer were able to accept their cancer and were able to cope with difficulties in their lives, which bolsters their psychological resilience. Zamora et al. (2017) explained that these childhood and adolescent cancer survivors are able to find meaning in their lives as a result of their increased emotional maturity and psychological self-assurance. Krok and Telka (2018) observed that cancer patients relied on their mental meaning structures to interpret meaning in a variety of situations.

According to Park et al. (2010), post-traumatic growth was a result of finding meaning in one's cancer. They discovered that younger cancer patients were able to gain a better understanding of how growth can reduce symptoms such as intrusive thoughts, which has significant clinical implications (Park et al., 2010). Vickberg et al. (2000) emphasised that the positive meaning has contributed to enhanced well-being by reducing psychological distress. Even though cancer altered how young cancer survivors perceive themselves, Zebrack and Chesler (2001, p. 253) argued that the positive or negative nature of this change depended on the meaning they ascribed to their experience.

According to Krok (2018), having a sense of purpose in life enabled young people to evaluate and organise their day-to-day experiences, identify what was important to them, and direct their efforts to overcome potential obstacles. Jones et al. (2010) identified seven significant themes regarding the experience and meaning of cancer survivorship among Latino adolescents and emerging young adults, including 1) gratitude, 2) humour or a positive attitude, 3) empathy for younger children with cancer, and 4) God or faith. 5) Cancer has significance or has altered my life; 6) familial support; and 7) staff relationships (Jones et al., 2010). These were crucial in helping them making sense of their cancer experience and incorporating that meaning into how they viewed their relationships, values, and faith, which all helped them cope. This also implied that MIL helps cancer patients form more optimistic views of their illness by interpreting significant life circumstances and effectively integrating them into the overall picture of the disease (Krok & Telka, 2018). In contrast to Zebrack and Chesler (2001), adolescent life is frequently disrupted, which may increase the likelihood of survivors worrying, not believing they are cured, and developing a poorer self-image.