

HEALTH-RELATED QUALITY OF LIFE: A STUDY AMONG YOUNG ADULT CANCER SURVIVORS

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This research project is submitted in partial fulfilment of the requirements for the Bachelor of Social Science (Hons) Psychology, Faculty of Arts and Social Science, Universiti Tunku Abdul Rahman.

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HEALTH-RELATED QUALITY OF LIFE AMONG CANCER SURVIVORS ${\bf APPROVAL\ FORM}$

This research paper attached hereto, entitled "Health-Related Quality of Life: A Mixed Methods Study Among Young Adult Cancer Survivors" prepared and submitted by Jefferson Ng Khai Qiang and Lai Yong Guang in partial fulfilment of the requirements for the Bachelor of Social Science (Hons) Psychology is hereby accepted.

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Table of Content

		Page	
Abstract		i	
Declarat	on	ii	
List of T	ables	iii	
List of G	raphs	iv	
List of A	bbreviations	v	
Chapters			
I	Introduction	1	
	Background of Study		1
	Problem Statement		3
	Research Questions		5
	Research Objectives		5
	Research Hypotheses		6
	Significance of Study		6
П	Literature Review	9	
	Cancer Survivorship		9
	Cancer Survivorship among Young Adults		10
	Cancer Survivorship and Adjustment to Life		12
	Positive Psychology and Health-Related		14
	Quality of Life		
	Mixed Methods in Exploring Health-Related		15
	Quality of Life		
	Crisis and Challenges among Young Cancer		16
	Survivors		

	In the Malaysian Context		17
	Theoretical Framework		18
	Conceptual Framework		19
III	Methodology	23	
	Research Paradigm		24
	Research Design		25
	Ethical Consideration		28
	Instruments		29
	Interview Protocol		31
	Data Collection		33
	Procedure for Quantitative Data Collection		34
	Procedure for Qualitative Data Collection		35
	Quantitative Data Analysis		36
	Qualitative Data Analysis		36
	Mixed Methods Data Analysis		38
IV	Results and Findings	39	
	Quantitative Survey		39
	Qualitative Interview		44
	Converging Data		64
V	Discussion and Conclusion	68	
	Discussion: Quantitative Survey		68
	Discussion: Qualitative Interview		7 4
	Discussion: Converging Data		80
	Implications of Current Research		82

	Limitations	and Recommendations for Future		83	
	Research				
	Conclusion			84	
References			86		
Appendices					
Appendix A		Quantitative Questionnaire			127
		Sample			
Appendix B		Qualitative Interview Informed			133
		Consent Form Sample			
Appendix C		Personal Data Protection			136
		Statement Sample			
Appendix D		Turnitin Originality Report			137
Appendix E		Action Plan			143
Appendix F		Supervisor's Comment on			144
		Originality Report			
Appendix G		Evaluation Form			145

Abstract

Along with the advancement of medical technologies, the prevalence of young adult cancer survivors in Malaysia is on the rise. However, less is known about the health-related quality of life (HRQOL) as perceived by these survivors over the course of their survivorship trajectory. This mixed methods research was to explore how variables were to influence the HRQOL of young adult cancer survivors in Malaysia. Pearson product-moment correlation test was conducted with the objective to examine the relationship between time since recovery and HRQOL of young survivors. Comparative statistical analysis such as one-way analysis of variance (ANOVA) and independent sample t-test were to determine the group differences of educational level and gender with HRQOL respectively. Semi-structured interviews enhanced the exploratory process of understanding perceived HRQOL of young survivors during their survivorship. Positive correlation, although not statistically significant, was found between time since recovery and HRQOL, while having tertiary education (except Doctorate degree) and the male gender were protective factors against low quality of life among young survivors. Interview findings revealed that physical dysfunctionality, social stigmatization, and inability returning to work were major sources of their HRQOL disturbance; however, the disturbances were encountered with perceived optimism and hopefulness. This research contributes a comprehensive baseline understanding of HRQOL among young Malaysian cancer survivors. As most researches were done among older adult cancer survivors or paediatric cancer survivors, this research raises greater awareness for the need of interventions tailored for this population in efforts to promote their well-being, and reducing cancer-related mortality.

Keywords: Health-related quality of life, young cancer survivors, mixed methods

We declare that the material contained in this paper is the end result of our own work and that due acknowledgement has been given in the bibliography and references to ALL sources be they printed, electronic or personal.

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List of Tables

Table	S	Page
1	Demographic and Clinical Characteristics of Quantitative Survey	39
	Respondents	
2	Descriptive Statistics and Correlation Between Time Since Recovery	42
	and HRQOL	
3	Descriptive Statistics and One-Way Analysis of Variance on Level of	43
	Education and HRQOL	
4	Descriptive Statistics and Independent Sample t-test on Genders and	44
	HRQOL	
5	Demographic and Clinical Characteristics of Qualitative Interview	45
	Respondents	
6	Summary of Themes and Subthemes	46

List of Figures

Figu	nres	Page
1	Conceptual Model of HRQOL with Domains of Physical Comforts,	22
	Psychological Functioning, and Social Relationship	

List of Abbreviations

No.	Abbreviation	Full name	Page
1	HRQOL	Health-related quality of life	2
2	IMTJ	International Medical Travel Journal	3
3	ICU	Intensive care unit	21
4	NCSM	National Cancer Society of Malaysia	28
5	SERC	Scientific and Ethical Review Committee	28
6	FACT	Functional Assessment of Cancer Therapy	29
7	FACT-P	Functional Assessment of Cancer Therapy for	29
		prostate cancer	
8	FACT-G	Functional Assessment of Cancer Therapy for	29
		general cancer	
9	PWB	Physical well-being	29
10	SWB	Social well-being	29
11	EWB	Emotional well-being	29
12	FWB	Functional well-being	29
13	EORTC QLQ-C30	European Organization for Research and	29
		Treatment of Cancer Quality of Life	
		Questionnaire Core 30	
14	FLIC	Functional Living Index – Cancer	30
15	QLI	Quality of Life Index	30
16	ANOVA	One-way analysis of variance	36

Chapter I: Introduction

Background of Study

Cancer, a name given to a collection of disease, begins with the abnormal cell growth in which cells divide uncontrollably beyond their usual boundaries and spread to nearby organs during the process known as metastasis (National Cancer Institute, 2015c). According to Bray, Ferlay, Soerjomataram, Siegel, Torre, and Jemal (2018), cancer is one of the most common diseases, with more than 18 million people diagnosed worldwide. Past literatures have allocated much focus on either childhood cancer or researches on the aged population, but the number of adolescents and young adults diagnosed with cancer is on the rise. In the United States alone, about 70,000 young people aging from 15 years to 39 years old are diagnosed with cancer each year, which accounts for about 5% of the nation's cancer diagnosis (National Cancer Institute, 2018e). Due to the advancement of treatments for cancer, the five-year survival rate for leukaemia (a type of blood cancer typically diagnosed among the younger generation) has increased drastically to 84% in the year 2009, as compared to 48% in the 1970's (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014).

Cancer in Malaysia is gaining attention from medical practitioners as well as health science researchers due to the increasing amount cancer incidence, where more than 18,000 new cancer cases were diagnosed in year 2007, according to the National Cancer Registry (Azizah, Nor Saleha, Noor Hashimah, Asmah, & Mastulu, 2015). The most common type of cancer diagnosed are female breast cancer (17.7%), colorectal cancer (13.2%), and trachea, bronchus, and lung cancer (10.2%). Lymphoma, the cancer of the lymphatic system, commonly affects the younger generation with the age group of 15-24 years, in which 20.9% males and 17.7% females were diagnosed with the disease in Malaysia; making lymphoma the fourth most common cancer (Azizah et al, 2015).

As defined by the National Cancer Institute (2019g), survivorship is a state of survival, which includes multiple aspects of physical and psychosocial issues on cancer, which goes beyond cancer diagnosis and treatments. Since the initial diagnosis of cancer and throughout the treatments, physical symptoms such as tiredness, nausea, and pain are usually cancer-related concerns raised by people affected by cancer (Von Gruenigen et al., 2009). With such, research done by Keim-Malpass, Mihalko, Russell, Case, Miller, and Avis, (2017) had shown that these physical symptoms were highly associated with poor health-related quality of life (HRQOL). This has drawn much attention from researchers on the HRQOL among surviving adolescents and young adults from cancer, in efforts to improve their quality of life during survivorship.

Health-related quality of life (HRQOL) is understood as the patients' appraisal of their health status and perceived well-being through domains of physical, health, psychological, emotional, and social functioning (Anthony et al., 2014). Using the quality of life concept as a foundation, HRQOL incorporates factors that cause an impact upon an individual's life; however, it is focused specifically on those that are part of an individual's health (Torrance, 1987). Moreover, the measures of HRQOL express the domains of health (e.g. functionality and well-being) more extensively than the domains of quality of life (Karimi & Brazier, 2016), making HRQOL a more distinctive measure of health outcomes among cancer survivors. Functionality refers to the ability of an individual to perform predefined activities, while well-being refers to an individual's feelings and emotions (Hays & Reeve, 2010). HRQOL is also said to be a measurement of an individual's self-perceived health status (Moons, 2004). Therefore, in the context of cancer, HRQOL refers to stressors in relation to cancer diagnosis, including treatment burden, daily functioning ability, resilience in facing the recurrence of the disease, and adapting to uncertainty in hope to achieve positive well-being (El-Shami et al., 2015).

Problem Statement

Recently, technologies developed in Malaysia's healthcare have been growing exponentially with more integrated and advanced equipment in treating diseases. Healthcare in Malaysia was recognized for the excellent performance at the International Medical Travel Journal (IMTJ) Medical Travel Awards 2018 (Malaysia Healthcare Travel Council, 2018) and was ranked first in the Best Healthcare in the World category of the 2019 International Living Annual Global Retirement Index. With such advanced technologies, more Malaysians are recovering from once-known deadly diseases, such as cancer. In 2018, there were more than 17,000 people surviving from cancer with an age-standardized mortality rate of 85.5 per 100,000 worldwide (Ferlay et al., 2018). Despite completing cancer treatments and recovering from it, cancer survivors continue to experience the impact of cancer and its treatments (Khan, Mant, Carpenter, Forman, & Rose, 2011) which will have substantial longterm effects on the HRQOL of these individuals (Rowland & Bellizzi, 2014). Among people affected by cancer, anxiety and depression are the major problems which further results in poor HRQOL (Schoormans, Czene, Hall, & Brandberg, 2015). Cancer patients experienced greater anxieties, especially when physical burdens were present (Boyle, 2003) and their physical disfigurements, such as a loss of hair and weight loss (Barnett et al., 2016); and as for cancer survivors, their fear of cancer progression or death was the source of their persistent anxiousness (Gallenkamp-Koch et al., 2016). Furthermore, post-treatment complications such as pain did contribute to poorer HRQOL (McCarthy et al., 2016). Hence, even though there was an increase of cancer survivorship, cancer survivors are still facing psychological distress and require post-treatment care.

Despite the increasing numbers of young cancer survivors, research on HRQOL were still limited to the older generation which are affected by cancer (Shin, Bartlett, & De Gagne, 2019). Moreover, researches previously done did report that patients diagnosed at a younger

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS age did suffer from poor quality of life in domains of sociality, emotionality, and cognitive functioning (Jansen, Herrmann, Stegmaier, Singer, Brenner, & Arndt, 2011). Currently, many services are available for patients undergoing treatment; however, there is a lack of psychological interventions tailored for cancer survivors, specifically young cancer survivors (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Psychological interventions, such as wellness programs were to be used to improve the HRQOL of cancer survivors in domains of their psychological well-being and health measures (Chambers et al., 2015). Paediatric cancer survivors also reported that they did not receive any form of cancer-related follow-up within 2 years, indicating a lower opportunity for detection of recurrence and increased mortality of young cancer survivors (Nathan et al., 2008). Without proper care on HRQOL of young survivors, the National Cancer Institute (2012a) reported that young survivors may develop higher levels of anxieties, as well as some adverse behavioural, social, and physical outcomes. Although past literatures had highlighted the negative outcomes from poor HRQOL among young cancer survivors, research on this specific age group is still lacking with only few explorations on their psychological aspects (Thompson, Palmer, & Dyson, 2009). As a result of this issue, development of more appropriate survivorship programs or evaluation of current ones has been significantly restricted, leading to more psychological problems in the future (Mattson, Demshar, & Daly, 2013).

Apart from quantitative studies done in the Malaysian context, there are no recent study done on an in-depth level regarding the psychological aspects of post-treatment cancer survivors. Even with past qualitative studies, most of them focused on cancer screening programs (Abdullah & Su, 2010; Farooqui et al., 2013), cancer awareness (Wong, Wong, Low, Knoo, & Shuib, 2009), and cancer experience (Yusuf, Hadi, Mahamood, Ahmad, & Keng, 2013), but none were on psychological domains. Lacking of in-depth understanding on cancer survivors is a significant barrier for researchers or mental health practitioners in

Malaysia to properly develop psychological interventions to improve better psychological well-being of surviving cancer patients. Hence, taking the benefits of both quantitative and qualitative research into account, the current research incorporated two distinctive methods and was conducted using mixed methods as the foundation of the research design.

Research Questions

- 1. Does the time since recovery correlates with the HRQOL as perceived by young adult cancer survivors?
- 2. Are there any significant difference between the level of education with the HRQOL as perceived by young adult cancer survivors?
- 3. Are there any significant difference between gender groups on their perceived HRQOL?
- 4. How do young adult cancer survivors perceive their HRQOL during cancer survivorship?
- 5. What are the factors that influence the perception of HRQOL as perceived by young adult cancer survivors?

Research Objectives

- To examine the correlation between the time since recovery and the level of HRQOL
 as perceived by young adult cancer survivors.
- 2. To determine the difference between the education level and the level of HRQOL as perceived by young adult cancer survivors.
- 3. To investigate the difference between gender groups on their perceived HRQOL.
- 4. To understand the perception of HRQOL as perceived by young adult cancer survivors.
- 5. To explore the factors that influence the perception of HRQOL as perceived by young adult cancer survivors.

Research Hypotheses

- The time since recovery is positively correlated with the HRQOL as perceived by young adult cancer survivors.
- There is a significant difference between the level of education and the HRQOL as perceived by young adult cancer survivors.
- 3. There is a significant difference between gender groups on their perceived HRQOL.

Significance of Study

In Malaysia, cancer death was placed fourth on the list of disease mortality, in which cancer had accounted for 12.6% of all deaths in the local hospitals (National Cancer Institute, 2018f). However, with proper preventive measures and greater awareness in cancer prevention, cancer is considered as a preventable disease as up to 50% of cancer are medically proven to be preventable by the World Health Organization (2019). For example, cervical cancer has a nearly 99% preventable rate if adolescents acquire the knowledge on human papillomavirus (HPV) vaccination and are vaccinated between ages of 15 and 26 years old (National Cancer Institute, 2017d). Cancer awareness has starting to shift towards the younger generation because they usually perceive cancer as an "elderly disease" where the general population affected by cancer is usually the aged population (Ershler, 2003); however, cancer no longer affects only the aged population. In accordance to a scholar review done by Barnett et al. (2016), many women were experiencing a lack of medical information regarding on health promotion, particularly on cancer, leading to shallow awareness on the disease. Subsequently, adolescents too desire for information concerning on disease treatments, its side effects, as well as access to supportive care upon completing treatment cycles (Hauken, Larsen, & Holsen, 2013; Mattson et al., 2013). Therefore, this current study hopes to shine lights in improving lives of cancer survivors upon their treatment completion,

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS by contributing to the pool of knowledge on cancer survivorship, specifically for young adults.

The emergence of more researches on the psychological aspects of cancer survivors, such as this current paper, promotes the development of individualized interventions in an effort to improve the lives of cancer patients after their completion of cancer treatments. Selfmanagement interventions, for example, were widely used among cancer survivors in promoting personal HROOL through the practice of healthy social relationships (Paterson, Robertson, & Nabi, 2015) and reduction of psychological distress (Kim, Kim, & Mayer, 2017). Moreover, wellness programs are significant in improving health of patients and were taken into consideration by medical practitioners as alternative treatments for people with critical illnesses such as cancer (Upchurch & Rainisch, 2015). Research on HRQOL also reported an enhancing effect when cancer survivors participated in community-based wellness programs (Mohammadi, Sulaiman, & Koon, 2013). Moreover, oncological psychologists and cancer counsellors will also benefit from such research upon establishing interventions for psychologically disturbed cancer survivors. Quality of life of cancer survivors can be enhanced through tailored interventions which focused on the comorbidities and psychosocial aspects (Highland, Hurtado-de-Mendoza, Stanton, Dash, & Sheppard, 2015). In addition, Osborn, Demoncada, and Fueurstein (2006) found that deliberate psychological interventions were effective in emotional stress-reduction as well as enrichment of cancer survivors' quality of life. After all, psychological interventions are considered as an inexpensive yet effective method in improving one's psychological wellbeing (Gordon, Beesley, & Scuffham, 2011).

Research in the field of social science has been revolving around two distinctive methodologies: quantitative and qualitative. With the recognition of the importance of both methodologies, the prevalence of mixed methods studies continues to increase during the past

few decades (Teddlie & Tashakkori, 2009). The increased interest in mixed methods research is partly due to the opportunity for researchers to maximize the strengths of both quantitative and qualitative approaches, at the same time disputing the weaknesses in both approaches. (DeCuir-Gunby & Schutz, 2017). By taking both approaches into account, the results from mixed methods studies usually provide a comprehensive view, and allow the formation of new dimensions of HRQOL in this current research (Gough, Koffman, Ross, Riley, & Judson, 2019). Moreover, the growth of mixed methods research on cancer survivors in the Malaysian context is to promote the understanding and investigation of psychosocial and cultural factors, in efforts to spread the awareness of cancer in the country (Lim, 2011). Hence, the current research which utilized the methodology of mixed methods research will further encourage the initiative.

Chapter II: Literature Review

Cancer Survivorship

By definition, survivorship is a state of being alive since the diagnosis of a chronic disease until later years, regardless of health outcomes (Ness, Kokal, Fee-Schoroeder, Novotny, Satale, & Barton, 2013). Cancer survivorship researches were done in hopes to explore greater understandings and denote physical, psychosocial, and economic changes among people affected by cancer (National Cancer Institute, 2014b).

Cancer survivors vary by age, ranging from infants to elderlies 65 years and above (Lews-Patterson, Palos, Dains, & Jackson, 2016). Among all the age groups of cancer diagnosis, childhood cancer was reported as having the highest 5-year survival rate, with an overwhelming 85% in year 2014 (Ward, DeSantis, Robbins, Kohler, & Jemal, 2014). Since paediatric cancer survivors are to live decades longer than most adult cancer survivors, it was found that as these children develop into adulthood, they were to suffer greater chronic health complications (75%) and development disabilities or life-threating late effects (37%; Kopp, Gupta, Pelayo-Katsanis, Wittman, & Katsanis, 2012). Research on young adults who suffered childhood cancer reported significant declines in physical functioning and mental health status (Oeffinger, Mertens, & Sklar, 2007), and at the same time, these individuals were reported to be unaware of their health complications (McCarthy, Campo, & Drew, 2013).

On the other end of the continuum, adults aging 65 years and above are 2.5 times greater in developing cancer (Vrdoljak et al., 2011), and the advancement of technologies result in this population representing the major age group of cancer survivors (Parry, Kent, Mariotto, Alfana, & Rowland, 2011). Due to old age and decline in developmental functioning, older survivors usually portray poorer health status, together with more severe chronic conditions, such as hypertension, and cardiovascular disease (Holmes, Nguyen, Nayak, Oh, Escalante, & Elting, 2014). Despite of health complications, studies have shown

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS that older survivors are more cooperative in preventive care services (Lowenstein, Ouellet, Dale, Fan, & Mohile, 2015) due to the desire for independent functioning and cognition maintenance, as compared to their younger counterparts whom they focused upon prolonging their survival (Fried, Bradley, Towle, & Allore, 2002).

Survivorship care. Defining cancer survivorship through a holistic approach enables clinicians to understand that the care for survivors is part of an integral process in cancer survivorship care (Shapiro, 2018). Shapiro also emphasized that cancer survivorship care involves members of the survivor's family, friends, and his or her primary caregiver, raising an idea that cancer is not a disease to be experienced alone. Furthermore, the goals of survivorship care are to: first, reduce risks of cancer recurrence and emphasizing on health promotion; second, alleviate physical and psychological effects after treatments (Kiserud, Dahl, & Fossa, 2018). Interventions toward greater survivorship care involve health promotion and wellness, in which can be done through increased physical activities (Burke, Wurz, Bradshaw, Saunders, West, & Brunet, 2017). Review by Burke et al. (2017) indicated that physical activity promotes greater HRQOL and reduces symptoms of treatments such as physical pain. Moreover, self-management was reported as an effective approach in survivorship care, evidenced by a study on prostate cancer survivors (Skolarus, Wittmann, & Hawley, 2017). Self-management, such as weight control (Ligibel et al., 2014), dietary practice (Schwedhelm, Boeing, Hoffmann, Aleksandrova, & Schwingshackl, 2016), and smoking cessation (Ramaswamy, Toll, Chagpar, Judson, 2016) empowers survivals to greater self-care, which was found to be a more effective alternative than specialized cares in institutions (McCorkle et al., 2011).

Cancer Survivorship among Young Adults

Through research, it was found that young cancer survivors possess a greater tendency than their healthy peers to develop symptoms of anxiety and post-traumatic stress

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS disorder (PTSD), as the aftermath of cancer treatments (Stuber et al., 2010). A longitudinal cohort study involving 589 childhood cancer survivors also found that these survivors were experiencing co-morbidities raised from cancer treatments, such as functional impairments and psychological distress (Stuber et al., 2010). In contrast, positivity was discovered among young cancer survivors in qualitative studies (Benedict, Victorson, Love, Fuehrer, Lazard, Shaffer, Linscott, & Zachary, 2017; Philips & Jones, 2014). Despite the hardships of cancer treatments, 11 out of 19 participants in interviews done by Benedict et al. (2017) were living through their lives with optimism and full of hope, and with such positivity they gain better autonomy in which they were involved in volunteering and advocacy. Survivors of childhood cancer also portrayed similar degree of optimism and their strength of survival arises from their positive attitude upon facing the disease (Philip et al., 2014). Strengths from family members as well as doctors and nurses were found to be empowering young cancer survivors to strive through the disease (May, McGill, Robertson, Anazodo, Wakefield, & Sansom-Daly, 2017). A 17 years-old survivor of cervical cancer shared that medical staffs were professional and caring during her stay in the hospital for treatments, this is also similarly reported in the study done previously by Philip et al. (2014).

To the current researchers' knowledge, there were no qualitative study specifically done on young cancer survivors aging from 18 to 25 years old, resulting in the cancer survival experiences among this population were not empathically understood. In addition to the lack of understanding, evidences have shown that patients within this age group usually find themselves treated either with the use of paediatric or adult interventions (Thomas, Albritton, & Ferrari, 2010; Zebrack et al., 2013). Hence, in regards of this issue, Sodergren et al. (2018b) conducted an intensive study involving young adults (14-25 years) and older adults (26-60 years) to distinguish different impacts of cancer on the HRQOL between these two population. In the study, it was found that younger people elicited perspectives upon

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS dealing with the impacts of cancer differently from those of older cancer sufferers, and further review of literatures explained that this is due to previous experiences of illnesses or life challenges (Snöbohm & Heiwe, 2013); older people were more tolerant towards chronic illness as a result of life experiences. This study reported young adults experienced lower HRQOL, but this result was oppositional towards those done using quantitative method. An integrative literature review involving 15 quantitative research articles reported that survivors of childhood cancer and young cancer patients did experience better quality of life than their healthy counterparts (Shin, Barlett, & De Gagne, 2019). The controversy between the degree of HRQOL is still debatable as several study results indicated older cancer survivors have greater HRQOL due to extensive palliative care (Sodergren et al., 2017a), better social functioning, and financial stability (Quinten et al., 2015).

Cancer Survivorship and Adjustment to Life

The prevalence of cancer survivors is on the rise over the past decade due to the advancement of technologies and improved professional diagnostic procedures (Robison, 2004). For long-term caregivers of cancer survivors, it is critical to realize that once the treatment was completed, post-treatment challenges (e.g. symptom burden) will still be present for the survivors to overcome. Hence, adaptation of cancer survivors to cancer and their survival is now an essential aspect in cancer survivorship care (Jacobsen & Jim, 2011). Cancer survivors are encouraged to always stay vigilant through learning, pharmacological education, self-management, and psychosocial interventions in order to help in adjustment of life (Ganz, 2001). Past literatures had shown significant association between mental adjustment styles and HRQOL among people affected by cancer (Johansson Ryden, & Finizia, 2011; Rottmann, Dalton, Christensen, Frederiksen, & Johansen, 2010). Mental adjustment is conceptualized as responses in regards to the cognitive and behavioural processes, and in this context, the processes towards the survivorship of cancer (Greer,

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS

Moorey, & Watson, 1989). According to the National Cancer Institution, paediatric cancer survivors had higher chances in presenting symptoms of anxiety and post-traumatic stress disorder (PTSD) as they transitioned into adulthood (Stuber, Meeske, Krull, Leisenring, Stratton, & Kazak, 2010) and survivors were more likely to have lower self-esteem as compared to healthy individuals (Servitzoglou, Papadatou, Tsiantis, & Vasilatou-Kosmidis, 2018). Thus, this is one of the risk factors in causing cancer survivors to experience difficulty in returning to their normal life and in the meanwhile, social relationship was acting as a main role in accelerating the progress of adjustment among cancer survivors.

Gender differences. Upon coping with the disease and adjusting to normality, men and women tend to possess different adjustment styles, as evidenced in past literatures (Mehrabi, Hajian, Simbar, Hoshyari, & Zayeri, & 2015; Spendelow, Eli Joubert, Lee, & Fairhurst, 2017). During the transitioning from cancer treatments to survivorship, men were reported accepting their weaknesses (Oster, Hedestig, Johansson, Klingstedt, & Lindh, 2013) while adopting a more flexible identity on masculinity (Maliski, Rivera, Connor, Lopez, & Litwin, 2008). This results in men became associated in healthier eating habits and positive behaviours, such as going for their medical appointments (Maliski et al., 2008). In contrast, women embraced religious beliefs and practices as coping strategies in which these cancer survivors sensed emotional comforts and hopefulness through these beliefs (Thune-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2011). Further literature exploration showed that minorities with negative religious adjustments resulting in poorer mental health among breast cancer survivors (Hebert, Zdaniuk, Schulz, & Scheier, 2009). Although both genders elicited differences in cancer survivorship adjustments, similarities were also found between genders. Avoidance was reported by a great number of cancer patients, both men and women, whereby they engaged in active attempts to distract themselves from the disease, such as distraction (McSorley, McCaughan, Prue, Parahoo, Bunting, & O'Sullivan, 2014) and alcohol abuse

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS (Hanly, Mireskandari, & Juraskova, 2014). A study done by Taylor and Stanton (2007) had found that avoidance as a coping strategy can only benefit people affected by cancer within a short period of time, but in the long term, avoidance was associated with higher psychological distress.

Positive Psychology and HRQOL

Positive psychology is intercorrelated with HRQOL in which interventions built upon the basis of positive psychology promote subjective well-being and quality of life, such as life satisfaction, resilience, and positive affects (Ho et al., 2016). In regards with that, positive psychology took an important role among cancer patients or survivors during their treatment process as well as future adjustment to life after their recovery. Positive psychology is a subdomain in the field of psychology developed by Martin Seligman in 1998. It is defined as a psychological theory, research, and interventions in understanding the positive, adaptive, and creative aspects of human behaviours (Seligman & Csikszentmihalyi, 2000) involving positive emotions such as happiness and satisfaction (Park, 2015). Since positivity or optimism is one of the aspects of HRQOL, staying positive can help in promoting better quality of life. Studies had shown that dispositional optimism could be responsible in developing better HRQOL outcomes, such as resilience among cancer survivors (Jurbergs, Russell, Long, & Phipps, 2007; Stam, Grootenhuis, Caron, & Last, 2006). Young adults who are more positive-oriented or in other words, optimistic, expressed greater self-efficacy on their ability in handling physical challenges during their process towards recovery or after they recovered (Kurtz, Kurtz, Given, & Given, 2008). Consequently, staying positively was more likely to engage in behaviours that effectively increase their endurance towards pain in psychological terms. This was evidenced by a study reporting that optimism was associated with positive affection, conceptualizing that perceptions of pain can be changed through positive mind (Logan & Rose, 2005). Although researchers understand that staying positive

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS can increase the quality of life, but it is difficult to maintain the level of positivity without proper physical and psychological care or support groups to assist them in identifying the impact of their experiences (Farya, Phillips, & Jones, 2013).

Mixed Methods in Exploring HRQOL

Through quantitative surveys, HRQOL of cancer survivors has been extensively studied; however, only a few researchers have incorporated a qualitative component into their quantitative research to explore the HROOL as perceived by cancer survivors. Within those that utilized the methodology of mixed method in cancer research, social support was reported as a significant factor which positively associate with the increasing quality of life as perceived by Chinese breast cancer survivors (Cheng, Sit, Cha, So, Choi, & Cheng, 2013). The result indicated that the increase of quality of life is associated with healthy social support, rather than the number of people providing the support. This significance was explored through semi-structured interviews as the Social Support Questionnaire (SSQ-6) used by Cheng and colleagues provided only surface information of the domains of social support among cancer survivors (Sarason, Sarason, Shearin, & Pierce, 1987). Furthermore, qualitative data obtained from cancer survivors promotes the understanding of the role of supportive care for these survivors, as reported by Paterson, Grzegorz, Nandwani, Chaudhury, and Nabi (2017) in their research on men with prostate cancer. These men spoke about their concerns which disrupted their perception towards survivorship, such as the feeling of dying and death, and the uncertainty about their future (Paterson et al., 2017). The comprehensive data from both questionnaire and interview provided new insights for the unmet needs as experienced by prostate cancer survivors, further encouraging the development of post-cancer care for these survivors.

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS Crisis and Challenges Among Young Cancer Survivors

Currently, many services are available for patients undergoing treatment; however, there is a lack of psychological interventions tailored for cancer survivors, specifically young cancer survivors (Sansom-Daly, Peate, Wakefield, Bryant, & Cohn, 2012). Paediatric cancer survivors also reported that they did not receive any form of cancer-related follow-up within 2 years, indicating a lower opportunity for detection of cancer recurrence and increased mortality of young cancer survivors (Nathan et al., 2008). Due to the nature of childhood cancer, the risks of developing treatment-related late effects (e.g. recurrence of disease and cardiovascular abnormalities) are higher among these individuals and they require survivorship care and sufficient surveillance for any symptoms of recurrence (Armstrong et al., 2016).

Peer supports and the importance of establishing social relationships with members of the society are essential during cancer survival among young adults (Wicks & Mitchell, 2010). However, there were young adults suffering from isolation as an effect of cancer (Grinyer, 2007). Feelings of isolation arise when young adults were starting to feel them being left behind from school due to frequent hospital visits and when their friends were lacking on cancer care knowledge (Taylor, Pearce, Gibson, Fern, & Whelan, 2013). In contrast, some young survivors were reported engaging in active social interactions and were described as portraying high levels of resilience and greater ability in returning to normality (Wallace, Harcourt, Rumsey, & Foot, 2007).

As adolescents were transitioning into adulthood, they often experienced developmental, social, and emotional changes which they required greater knowledge and supportive care needs than any other age groups (Shay, Parsons, & Vernon, 2017).

Nevertheless, study had found that 53% of young cancer survivors (15-39 years) were not receiving sufficient information and 35% were lacking of necessary service needs (Keegan et

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS al., 2012). Such information required by this population includes information on the recurrence of the disease, late effects of cancer, financial aids, and fertility issues. The lacking of these information and needs were associated with lower HRQOL (DeRouen et al., 2015) as well as an increased anxiety among young adult cancer survivors (Dyson, Thompson, Palmer, Thomas, & Schofield, 2012).

In the Malaysian Context

Cancer experience. For some, going through cancer is challenging and disturbing as cancer treatments shift a person's lifestyle and they even experience physical change in their bodies (Yusuf, Hadi, Mahamood, Ahmad, Keng, 2013). Hair loss (Chan & Ismail, 2014) and vomiting (Sun et al., 2005) were considered as the most distressing side effects upon treating the disease using chemotherapy. As reported by Farooqui et al. (2011), the experiences of participants throughout the treatment were overwhelmed by fears of its side effects and they developed strong negative perceptions toward the treatments. Such effects on the quality of life among these patients were widely studied (Korfage, Hak, Koning, & Essink-Bot, 2006), with results showing a decline in HRQOL due to fears and anxiety. To combat the side effects of treatment, specifically chemotherapy, patients were reported experimenting on complementary and alternative medicines (e.g. fruits and tea) while undergoing chemotherapy (Nies et al., 2018). Although this method seems sceptical, past literatures have found that diet rich in fruits and vegetables showed significant improvements in patients' overall quality of life and better coping abilities against the side effects of cancer treatment (Beatty, Oxland, Koczwara, & Wade, 2008), but more researches should be done in recent times to update on this matter.

Barriers related to cancer. Cancer treatments usually cause deterioration to physical functionality; however, through rehabilitation, one can recover from it and achieve normality to resume to daily life functioning, such as returning to work (Myhren, Ekeberg, & Stokland,

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS 2010). For cancer patients, returning to work indicates that they are able to return to normal life, which is highly associated with greater quality of life (Islam, Dahlui, Majid, Nahar, Taib, Su, & MyBCC study group, 2014). Flexibility, lighter workloads, and less work stress were indicated as factors for women to continue working even during treatments in government sectors. However, quantitative study on 256 breast cancer survivors reported that older women were at greater risk of losing their job (Su, Azzani, Tan, & Loh, 2017), especially for women working in private sectors. Qualitative study with 6 homogenous focus-groups, too, reported similar results whereby 70% cancer survivors lost their jobs after receiving cancer treatments (Tan, Loh, Su, Veloo, & Ng, 2012). It was reported that cancer patients do not return to their work partly due to the lack of social support at workplace (Fantoni, Peugniez, Duhamel, Skrzpczak, Frimat, & Leroyer, 2009), together with poor coping skills.

Theoretical Framework

Health-related quality of life (HRQOL) has been viewed as a goal that people desire across all life stages by global health organizations (World Health Organization, 2007). As HRQOL is conceptualized with multidimensional components and its diverse use in fields of both health and psychology, researchers are constantly searching for models of HRQOL to guide their research (Bakas et al., 2012). Within the pool of psychological journal articles, there are a variety of HRQOL models available, encompassing different health and illness conditions, developmental lifespan, and specified within individual, families, and communities; however, only one has incorporated both biomedical and social science perspective as one (Wilson & Cleary, 1995). In the Wilson and Cleary model of HRQOL, five components were discussed in relation to health: biological and physiological factors, symptoms, functioning, general health perceptions, and overall quality of life (Wilson et al., 1995), and these are considered as important domains of HRQOL among cancer survivors (Avoine-Blondin et al., 2017). Due to its wide coverage of domains, both biological and

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS psychosocial, psychology researchers were using it as a foundation to their studies (Janz et al., 2001; Daggett, Bakas, & Habermann, 2009), even in cross-culture research (Krethong, Jirapaet, Jitpanya, & Sloan, 2008). Moreover, in a study done among survivors of Hodgkin's lymphoma (a cancer commonly diagnosed among young adults; Smith, Ziogas, & Anton-Culver, 2012), determinants of HRQOL in this population was examine and was able to support the multidimensionality of the Wilson and Cleary model of HRQOL (Wettergren, Bjorkholm, Axdorph, & Langius-Eklof, 2004). Hence, the current research will continue to use this model as guidance, making it a baseline qualitative study in Malaysia to utilize it as foundation of HRQOL concepts.

However, despite the wide acceptance of the Wilson and Cleary model by many other researchers, it was reviewed that this model contains limitation (Bakas et al., 2012), in which this model did not include individual and environmental factors in conceptualizing the model for HRQOL. Environmental factors, such as social relationship was found to have association with HRQOL among cancer survivors with strong social support resulting in better appraisal of survivors' HRQOL (Devine, Parker, Fouladi, & Cohen, 2003). Therefore, further exploration and improvement have been made on the existing Wilson and Cleary model of HRQOL (Ferrans, Zerwic, Wilbur, & Larson, 2005).

Conceptual Framework

The use of HRQOL in assessing life qualities of individuals, especially patients, is mainly due to the wide array of aspects when defining qualities of life, in which some are irrelevant to health (e.g. freedom; Guyatt, Feeny, & Patrick, 1993). Upon measuring HRQOL, individuals from similar phenomena or cultural background may elicit perceptions differently, leading to unique and individualized meanings of HRQOL. People affected by cancer, both patients and survivors, portrayed similar yet some variations when it comes to defining the meaning of HRQOL. Defining the concept of HRQOL is difficult, due to its

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS multidimensionality (Farquhar, 1994); which the inclusion of HRQOL domains are depending on the aspects of interest during the process of conceptualization. While some components defined by researchers may be more complex which incorporate components such as one's degree of independence (World Health Organization, 1997), communication (Taylor et al., 2013), and financial impact (Fern et al., 2013), the main components in HRQOL usually includes physical, psychological, and social issues.

Physical comfort. Physical comfort has been the main trajectory for these people affected by cancer to define their life qualities upon diagnosis (O'Gara, Tuddenham, & Pattison, 2018). O'Gara and her colleague nurses reported all their six participants reflected uncertainty and vulnerability due to the physical discomforts of treatments. Living with pain and other physical consequences did show significant impact on HRQOL of these individuals (Desai, Law, & Needham, 2011; Hopkins, Suchyta, Farrer, & Needham, 2012). Similarly, in another qualitative study which involved 30 patients who were still undergoing treatment at that time, side effects on physical comfort caused by treatments were the foundation of these patients' definition of HRQOL (Sibeoni et al., 2018); the degree of physical comfort affected their quality of life. However, part of the participants in the study reported that regular physical activity was able to combat discomforts of such discomforts, mentioned by the participant who combated pain and quoted, "I began to play golf too: to let go and not think about anything." Sibeoni et al. (2018) concluded that through physical activity, patients were able to channel their negativity away from them and it acted as an escape from pain. In contrast, some cancer patients do not view pain as a major indicator for poor HRQOL (Reid, Swift, & Mehanna, 2017). Further exploration of the study discovered that positive social support served as a buffer between pain and poor HRQOL.

Psychological functioning. Despite the completion of cancer treatments, cancer survivors continue to dwell in various psychological consequences, such as depression (Yi &

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS

Syrjala, 2017), anxiety (Ross et al., 2016), and the fear of cancer recurrence (Cupit-Link,

Syrjala, & Hashmi, 2018). Although, over time, cancer survivors are able to return to

normality through psychological interventions, many still continue to experience

psychological distress (Shapiro, 2018). Insomnia, a type pf sleeping disorder, is highly

associated with depression and a review on the mutual effects of both distresses was found to

result in higher mortality risk among cancer survivors (Irwin, 2013), further leading to a

negative effect on HRQOL. Moreover, there is an increasing interest on cancer survivors and
their fear of cancer recurrence (Simonelli, Siegel, & Duffy, 2016) and it was found that most
younger survivors were experiencing higher degree of fear as compared to the older people
(Kiserud et al., 2018). Based on a review done by Yang et al. (2019), 31% to 85.2% of young
adults suffering from cancer were living with constant fear of the disease recurring, leading to
a poorer psychological functioning and overall HRQOL.

Social relationships. Cancer survivors surrounded with positive, supportive interpersonal relationships were reported to have greater well-being as compared to those who were lacking of such relationships (Schroevers, Helgeson, Sanderman, & Ranchor, 2010). Social supports served as a comfort zone for cancer survivors, especially adolescents and young adults in believing that they were accepted by the society and are taken care of by someone whom they entrusted (Dreyer, Schwarts-Attias, 2014). This was in line with the study done by Pattison, O'Gara, and Rattray (2015) which denoted on the importance of patient-physician relationship. The mixed-method, longitudinal study on cancer patients staying in the intensive care unit (ICU) reported that patients experienced a sense of security and this further promoted the patients' motivation towards recovery. Similarly, Sibeoni et al. (2018) also mentioned that the physician's ability to listen to patients reinforced the relationship between both individuals, and together with the presence of family members and supportive peers, patients reported better HRQOL. Cross-culture research, such as studies

from China, did report similar positive effect of supports from medical professionals on patients' quality of life (Song et al., 2016).

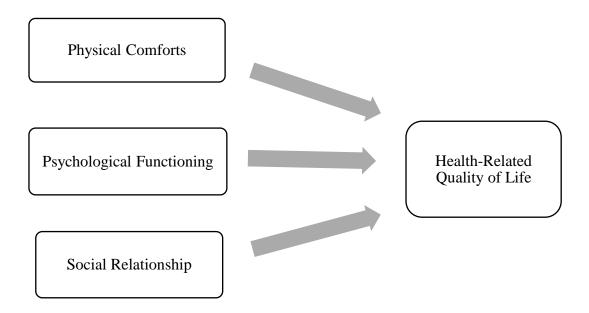


Figure 1. Conceptual model of HRQOL with domains of physical comforts, psychological functioning, and social relationship.

Chapter III: Methodology

"Qualitative research is a situated activity that locates the observer in the world"

(Denzin & Lincoln, 2018). It involves methods of interpretation and understandings to visualize the world. Unlike quantitative studies which objectify persons through rigid, directive psychological instruments, qualitative studies empower persons' experiences and enable individuals to immerse themselves into their holistic world (Mertens, 2015). Although quantitative research is able to generalize the results obtained to a larger population and also enables the correlation of two or more variables in a given context (Creswell, 2015), the typical mainstream psychological study fails to collect rich data as rating scales or multiple-choice questionnaires provide only restricted and structed information (Denzin et al., 2018). In contrast, qualitative research concerns on the richness of descriptions from individuals, further capturing the individual's perspective. Patients of critical illnesses, such as cancer, have different stories to be told, different experiences to be shared, and the nature of qualitative research enables the voices of these patients to be heard (Gough & Deatrick, 2015).

Given that there are strengths and weaknesses in each research approach, social science researchers are to bring both approaches together and incorporate the both methodologies together as a mixed methods research. A mixed methods research involves both objective quantitative survey and exploratory qualitative interviews to draw interpretations based on the combined strengths of both sets of data (Creswell, 2015). Hence, because of the comprehensiveness of mixed methods data, mixed methods study has gained interests among health psychologists, as evidenced by the emergence of mixed methods studies in mainstream research journals and the publication of the Journal of Mixed Methods Research (DeCuir-Gunby et al., 2017), together with the recognition in psychological researches.

The current research was conducted using the methodology of mixed methods research as its foundation. This chapter will further elaborate the research design, specifically convergent parallel design and its purpose, the recruitment of informants/participants, procedure of data collection, ethical obligations, and consideration on establishing validity and reliability of the research.

Research Paradigm

The methodology of the current research was built upon the constructivist/interpretativist paradigm whereby the concept aims to understand how people experience the world (Chilisa & Kawulich, 2012). Constructivists perceive that the reality is constructed based on social aspects (Creswell, 2007; Mertens, 2015). Therefore, multiple intangible realities can emerge, causing changes to the researchers' perceptions of reality throughout the research. However, constructivism aims to understand meanings and knowledge from multiple social constructs (Mertens, 2015), leading to a conclusion that the reality is limited to context and individuals in a given situation and cannot be generalized into the social norms (Chilisa et al., 2012). In the world of constructivists, the ways of knowing the reality is subjective to individuals, due to the nature of the socially constructed reality (Chilisa et al., 2012). The meanings of reality are based on human experiences and are influenced by the contexts where the individuals at, as well as cultural backgrounds. Therefore, because of the interactive process of obtaining knowledge, constructivists utilize a more personal and interactive method of data collection. Qualitative methods, such as interviews are essentials for researchers using the constructivist paradigm as foundation of their research in effort to understand human experiences (Mertens, 2015). The assumptions about the multiple social constructions of reality are to be acknowledged in the research and hence, research questions are not to be rigidly established prior to the study but they evolve as the research progresses. Researchers first construct a predominant question and subHEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS questions then evolve around it throughout the study (Chilisa et al., 2012). The predominant question usually explores the problem to be examined in the study, while the sub-questions are to serve as guidelines for researchers to obtain greater in-depth knowledge.

Research Design

Convergent parallel design. In convergent parallel design, quantitative and qualitative data were collected separately, but concurrently (Bazaley, 2018). The intent of this design it to combine both data sets from two distinctive approaches, providing a more wholesome understanding of the result than the results provided by each data sets alone (Creswell, 2015). Hence, this design is also known as a triangulation or concurrent mixed methods design (DeCuir-Gunby & Schutz, 2017). During the research using this design as a foundation, the quantitative and qualitative components do not influence one another during both the collection and analysis process. However, the final relationship between both data sets were formulated through integration and interpretation of both sets of results by practicing side-by-side comparison. Convergent designs enable researchers to support their findings from both quantitative and qualitative components with one another, or to triangulate the findings (DeCuir-Gunby et al., 2017).

As this design incorporates both approaches without influencing one another, it provides different insights and multiple perspectives for researchers, where one approach alone may not be able to elicit (Creswell, 2015). Moreover, the data collection process in this design is less time consuming, as data collection can be taken place during the same period of time (DeCuir-Gunby et al., 2017). This provides an advantage for the current research due to the limited time and resources available. However, this design possesses a risk of both data sets to diverge from one another, making the interpretation process difficult and complex (Creamer, 2018). Hence, researchers were required to start the data collection processes with the same measure (in this current research, the use of the same HRQOL instrument as

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS foundation; Creswell, 2015) and to collect additional data through follow-ups (DeCuir-Gunby et al., 2017).

Cross-sectional survey. The nature of cross-sectional surveys involves researchers collecting responses at different stages in a process, but measured at the same time (Clark-Carter, 2004). This design is time and cost-efficient, making it a widely used research design among quantitative researchers (Singh, 2007). The use of cross-sectional research produces exploratory, descriptive, or explanatory results (Neuman, 2007), making this the basic foundation for the current research as the current research incorporated both comparative and correlational methodologies in analysing the quantitative components. While comparative research make comparison between two or more distinctive groups to determine group differences, correlational research make predictions from one variable to another (Mertens, 2015).

Thematic analysis. Thematic analysis is a specific approach to qualitative study which draws upon theoretical concepts from hermeneutics (Palmer, 1969), and on engagement with subjective experience (Smith, Harre, & Van Langenhove, 1995). Even though thematic analysis aims to explore the experiences of participants from their perspectives, it embraces the recognition that such exploration will implicate the researcher's own perception of the world during the interaction between the researcher and the participants (Willig, 2008). The design requires an integrative process by engaging with texts and transcripts. This can be facilitated through a series of procedures, allowing researchers to develop themes and clustering them for further analysis (Willig, 2008).

Sampling method. Purposive sampling technique was used to recruit the research sample. Purposive sampling is a method of selecting individuals as participants in which these individuals are to be chosen purposely by the researcher, based on similarities in terms of characteristics or features that enable an in-depth exploration of a particular phenomenon

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS of interest (Frost, 2011). With participants of a sample sharing similar characteristics and from the same phenomenon, this sample is also known as a homogenous sample. Thus, in regards to the nature of purposive sampling-g and past literatures which yielded informative data through the use of purposive sampling (Smith, Eatough, Smith, Mihai, Weaver, & Sadler, 2018; Levy & Cartwright, 2015; McTiernan & O'Connell, 2015), the current research sample were able to provide useful results to fulfil the objectives of this research. Moreover, snowball sampling technique were incorporated in this study to obtain more samples.

Informants/Participants. A total of 66 respondents participated in the survey; however, 13 responses were incomplete hence removed. The final number of respondents was 53 young adult cancer survivors. The limited sample of young cancer survivors has been a limitation to the current research, which was reported by many similar researches in Malaysia (Knight, Hwa, & Hashim, 2015; Dubai, Ganasegeram, Alabsi, Alshagga, & Ali, 2012; Loh, Yip, Packer, & Quek, 2010; Suzana et al., 2009). This had resulted in the difficulty to estimate an effect size for the sample estimation in this current research. Moreover, despite having advanced technologies and publication of research articles throughout the decade, data on cancer epidemiology in Malaysia were currently not available (Lim, 2008), causing a greater challenge in determining the sample size to be estimated. The prevalence of cancer was mainly estimations from small cancer registries and private institutions available in Malaysia instead of data from the national consensus (Azizah, Decaraj, Bina Rai, Norbaiyah, Nooraiham, & Noorshila, 2010).

The sample size of thematic analysis revolves around the aim of the research and the resources present for the researcher to collect data (Howitt, 2016). For student research projects using this design, due to the limited time and resources, the number of participants is suggested to have in between three to six participants (Howitt & Cramer, 2011). Moreover, the guidelines validated that five participants are sufficient enough to provide a rich and

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS informative interpretation of on the individual's experiences (Smith, Flower, & Larkin, 2009). Hence, five cancer survivors participated in the interview.

Inclusion and exclusion criteria. Eligible criteria for participating in the current research included young cancer survivors aged between 18 to 40 years, diagnosed and completed treatments on the disease, and were literate enough to understand the nature of the current research. Participants with co-occurring psychological disorder were excluded from the research in order to maintain the homogeneity of the result.

Location of the study. Participants were recruited from the National Cancer Society of Malaysia (NCSM). NCSM was the first charitable organization in Malaysia that provides education, care, and support services for people affected by cancer (National Cancer Society of Malaysia, 2018), as well as the general public. NCSM had also hosted support groups and wellness activities for young cancer survivors since 2016.

Ethical Consideration

Ethical concerns were consulted with relevant bodies, such as UTAR Scientific and Ethical Review Committee (SERC) before the research is initiated.

Informed consent. Prior to the interview, informed consent was obtained from participants and they were briefed on the nature of the study. The consent form includes acknowledgements of the participants' right to withdraw from the study at any time without any consequences. Confidentiality on information of the participants was clearly specified. For example, audio recording is only for the use of the researchers themselves to facilitate during the transcription process and data analysis. The participants were informed on situations where the breach of confidentiality to relevant parties may occur (e.g. when the participant portrayed a risk of harming themselves or others), and details with relevant organisation to handle where necessary was clearly stated. Moreover, in the case of the

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS occurrence of psychological distress during the research, participants were given information on any relevant mental health services, such as the counselling service available in NCSM.

Instrument

Functional Assessment of Cancer Therapy. One of the widely used questionnaires for HRQOL assessment on cancer patients and survivors is the Functional Assessment of Cancer Therapy (FACT). The development of FACT scale was done with the objective of obtaining information about the health status based on the specific illness or treatment experienced by the respondent (Cella et al., 2016); therefore, several versions of FACT scales were developed in assessing HRQOL of patients specific illness, such as FACT-P for prostate cancer patients (Chu et al., 2014), and in assessing patients from different context (Arli & Gurkan, 2016). The general measure of the FACT scale, or otherwise known as FACT-G, is a 28-item questionnaire and utilize the Likert scale for measuring HRQOL (Cella et al., 2016). The questionnaire addresses the four primary domains of quality of life: physical well-being (PWB), social or family well-being (SWB), emotional well-being (EWB), and functional well-being (FWB).

Another widely used instrument to assess the HRQOL is the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30). Although the 30-item questionnaire has a similar structure and construct as the FACT-G scale, including the use of Likert scale and a recall period of 7 days (Aaronson et al., 1993), the current researcher favour the FACT-G scale over the EORTC QLQ-C30 scale mainly because of the clear organization of items in the questionnaire (Woo et al., 2016). The comparative article by Woo and colleagues (2016) indicated that the grouping of items according to subscales promotes a more systematic view of the questions, as compared to the EORTC QLQ-C30 scales which the questions were dispersed throughout the whole questionnaire without any specific order. Moreover, the presence of reversed items in the

FACT-G scale ensures the trustworthiness of the responses (Yost et al., 2013), as compared to the EORTC QLQ-C30 scale which does not involve reversed scoring. Lastly, the scoring

system as formulated in FACT-G scale is simpler and more convenient for the researcher; the

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS

scoring of EORTC QLQ-C30 scale requires researchers to convert the 1-4 numeric scores to a 0-100 scale and a higher score represent worse quality of life, while the scoring of FACT-G is much less complex (King, Bell, Costa, Butow, & Oh, 2014).

Scoring System. The quality of life was assessed using a Likert scale of 0-4, with the score "0" indicating "not at all" and "4" indicating "very much" for each respective item. Scores from reversed items were obtained by deducting the item score by 4. The subscale scores were obtained by multiplying the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. Finally, all subscale scores from 4 of the subscales were added to derive the total FACT-G score with a score range of 0-108. The higher the score, the greater the quality of life as perceived by the respondents.

Reliability. The reliability of the FACT-G consisting of 28 items in the current research is $\alpha = .97$, which is considerably high despite the small sample size.

Validity. The convergent and discriminant validity of the FACT-G scale was evaluated by Cella and colleagues (1993). Convergent validity was evaluated through examination of the association between scores on the FACT-G scale with those other similar measures completed by 316 cancer patients at the same time. The correlation coefficients were relatively high, indicating the constructs were corresponded to one another. On the other hand, divergent validity was evaluated through examination of the association between scores on the FACT-G scale with dissimilar measures. The correlation between the comparison was low, supporting the divergent validity. The other measures used for evaluating the validity of FACT-G scale were Functional Living Index-Cancer (FLIC) and the Quality of Life Index (QLI), which were commonly used quality of life scales.

Interview Protocol

The interview questions for this current research were formulated in reference with constructs of different HRQOL instruments, such as the Functional Assessment on Cancer Therapy (FACT) and questions that will elicit meanings of health-related quality of life (HRQOL) among these participants. During the interview, participants were initially be asked on his or her experiences of the diagnosis and treatment; then venture deeper into meanings of HRQOL; impact of the disease on HRQOL; and finally, efforts to improve HRQOL.

Reliability. In qualitative studies, reliability is often referred to the stability of responses in regards to multiple coders of data sets (Creswell, 2007), in which the term "coder" here refers to the current researchers who will develop themes during the analysis of data. The reliability was enhanced through obtaining detailed data as from the interview and transcripts, and developing codes or themes based on the transcripts. One key issue in establishing reliability of qualitative study is determining whether the codes or themes are comparable with one another, and seeking agreements based on the formulated codes or themes (Creswell, 2007). Hence, the transcripts of this current research were read independently and develop themes with individualized definition, which were then compared with themes among the researchers to reach an agreement of predominant themes. The process possesses flexibility; hence, researchers are to formulate themes consistently with the available resources and time (Creswell, 2007).

Validity. In qualitative research, one of the most questionable consideration is the importance of validation; in regards of its definition, how is it described, and what are the procedures taken to establish its validity (Creswell, 2007). There were several perspectives in the psychological research field viewing qualitative validation in terms of quantitative equivalents, utilizing validation methods in quantitative study onto the methodology of qualitative studies (LeCompte & Goetz, 1982), and then leading to criticism for its failure to

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS provide reliability and validity. However, Lincoln and Guba (1985) proposed alternative terms in defining the validity of qualitative research, such as credibility, transferability, dependability, and confirmability. Using this concept as guidelines, the current researchers utilized techniques, developed by Lincoln and Guba in establishing the validity of the research.

Credibility. To establish credibility, an alternative term for "internal validity", the current researchers prolonged the engagement in the field by exploring more in-depth of the participants' experiences (Lincoln & Guba, 1985). Triangulation of multiple data sources upon analysing the data will also be done by checking the data from different sources or methods for consistency of evidence across the sources of data (Mertens, 2011).

Transferability. Similar with external validation in quantitative studies, transferability of the current research findings between other researchers was established through developing thick descriptions upon analysing the data. Thick descriptions involve recording meanings which enable a particular episode or phenomenon to be characterized clearly with sufficient details (Schwandt, 2001), and give readers a sense of emotions, thoughts, and perceptions of the participants' experience (Holloway, 1997).

Dependability. Rather than reliability, researchers acknowledged that results are subjected to change and instability, but sought dependability of the result (Mertens, 2011). A dependability audit was conducted to ensure the quality and appropriateness of the research process.

Confirmability. Lincoln and Guba (1985) identified confirmability as the qualitative parallel to objectivity. Objectivity refers to the state where the researcher's judgement does not interfere with the result of the research. In qualitative studies, data and interpretation are not figments of the researcher's imagination; hence, achieving confirmability (Mertens,

2011). This was done by tracing the data to its source and checking the process of data analysis by a confirmability audit.

Data Collection

Demographics. Upon data collection, demographical information is essential to be obtained from participants as this information serve as a determination of whether the individuals are representative sample of the targeted population and are variables in research (Salkind, 2010). The demographic information of interest by the current researchers are:

- 1. Gender
- 2. Age
- 3. Ethnicity
- 4. Highest education level completed
- 5. Socio-economic status
- 6. Cancer type
- 7. Treatment type
- 8. Current health status
- 9. Age of diagnosis
- 10. Time since diagnosis

Questionnaire. The questionnaire was prepared in both paperback and in the form of an online survey using the online survey generator – Qualtrics[©]. The use of questionnaire in the form of an online survey facilitated the data collection process, in which the current researchers were able to reach out for more respondents through the snowball sampling method. The questionnaire consists of 3 sections. Section A includes necessary information on the questionnaire, such as nature of study and confidentiality of the study, and informed consent was obtained in this section as well. Section B was formulated with demographical questions while Section C was formulated with the FACT-G scale.

Semi-structured interview. The mechanism of thematic analysis works based on transcripts of semi-structured interviews (Willig, 2008). Researchers using thematic analysis practice semi-structured interview because open-ended and non-directive questions encourage rich and in-depth exploration of how participants make sense of their experiences. The purpose of a semi-structured interview is to serve as a platform for individuals to express themselves fully and share their experiences without being controlled by what results the researcher desired to have (Willig, 2008). Such interviews require the practice of rapport building and communicative skills, enabling researchers to engage in deeper understanding and further exploration on matter of interests (Frost, 2011). Researchers engaged in the interview with an open mind and display sincere empathy, at the same time trying to distance from prior knowledge regarding HRQOL (Avoine-Blondin, Parent, Lahaye, Humbert, Duval, & Sultan, 2017). This is to ensure experiences of participants are understood and explored without personal biases or pre-acquired concepts.

Reflective field notes. During interviews, researchers will usually immerse themselves in the field, in hopes to obtain rich description that exemplifies their qualitative research (Geertz, 1977). In the process, field notes were taken in recording any verbal and nonverbal behaviours observed by the researchers, as well as denoting the researchers' thoughts, feelings, and insights (Flick, 2014). Field notes were found to be a rich source of data in examining the meaning of participants' description of themselves and their actions in the interviewing context (Miles & Huberman, 1994), other than the transcription itself.

Procedure for Quantitative Data Collection

Young cancer survivors from the NCSM Young Cancer Survivors Group were approached and invited to participate in the survey. After checking the eligibility of the respondents using the inclusion and exclusion criteria as guidelines, the eligible respondents were briefed upon the nature of the study and informed consent was obtained. Respondents

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS were given the questionnaire to be completed. The questionnaire took between 15 to 20 minutes to complete. During the course of completing the questionnaire, respondents were given full autonomy to withdraw from the study if the respondents were uncomfortable to do so. The respondents were also provided with an area with maximal privacy and comfort upon completing the questionnaire. The respondents were thanked for participating in the research.

Procedure for Qualitative Data Collection

Respondents who had completed the survey were invited to participate in the interview. Prior to the commencement of the interview, participants were briefed upon the nature of the study and informed consent was obtained. Participants completed a brief demographic questionnaire. Data were collected through individual semi-structured interviews, in which participants were asked upon open-ended questions. The interview occurred in a range of 1 hour to 1 hour 30 minutes, depending on how detailed the participants' speech are. During the interview, the current researchers interacted with empathy and practiced active listening in effort to build greater rapport with the participants. A total of 5 participants were recruited for the interview. Upon completion, participants were asked to leave their contact details in the event that the researchers are to obtain clarification from the participants.

An enclosed room or counselling room in NCSM was used as the venue for the interview to secure the confidentiality of participants. Upon interviewing, the session was audio-recorded to facilitate the analysis process. The audio recordings were then be transcribed verbatim into text prior to data analysis. Transcription of the interview provides greater convenience for researchers to analyse the data as researchers do not have to replay and manoeuvre around the recordings. Moreover, a transcription enables researchers to notify any relationships between data and cases (Howitt, 2016), thus constructing a more holistic analysis.

Quantitative Data Analysis

Quantitative data was analysed using the Statistical Package for Social Sciences version 21 (SPSS, Inc., Chicago, IL) and tabulated. Descriptive statistics were calculated for both continuous (frequencies, mean, standard deviation) and categorical variables (frequencies, percentages). A Pearson product-moment correlation test were conducted in determining the correlation between time since recovery and HRQOL scores. The strength of the relationship was then reported based on the Cohen's rule of thumb as a guideline. Comparisons between groups of cancer survivors in terms of educational level with HRQOL score were performed in a one-way analysis of variance (ANOVA), while the comparison between gender groups and HRQOL score were performed using independent sample *t*-test. All tests of significance were one-sided and with *p* value < .025 was considered as statistically significant.

Qualitative Data Analysis

Step 1: Case familiarisation. The initial stage involved thoroughly reading the verbatim transcripts of the interviews, one case at a time. This is for the researchers to obtain a holistic picture of the interview and familiarity with the data (Frost, 2011). The transcripts were read repeatedly for a number of times to make known of the participant's verbal patterns, use of language, and the interview content. By doing as such, new perspectives might surface through each new reading of the transcript (Sibeoni et al., 2018). Upon reading the transcripts, the current researchers made attempts to summarise and comment on what has been said in the interview, which includes observations and reflections about the interview experience. At later stage, these comments were useful in seeking to confirm, change, or point our inconsistencies between cases. The use of metaphor was paid attention to as this enables researchers to make inductive descriptive notes through the participant's own words.

Step 2: Themes formation. With detailed familiarisation of the data, the current researchers began to identify themes for what has been said in the transcript. The process of transforming initial notes into emerging themes involved formulating concise phrases that represent conceptual understandings of the transcript. There was a relationship between the themes and the transcript; however, themes were expressed in more abstract terms. Themes are used to capture the experience of the phenomenon during the study (Sibeoni et al., 2018).

Step 3: Connections of themes. The identified themes were grouped together with similar concepts and contents to form broader themes, and this was done by looking at association between themes and connecting them together. Current researchers looked for the patterns among the themes and produce a structure that is helpful in highlighting converging ideas. The theme titles were compared with the transcripts to ensure that the themes developed were truly relating to what has been said in the interview. In the situation where the current researchers were stuck in the analysis, they restructured their views by thinking more conceptually rather than dwelling in previously identified themes (Howitt, 2016).

Step 4: Further analysis of cases. Since the study involved more than one case, the analysis proceeded to other cases through the same process. Themes from the first case were used subsequently in other cases but, alternatively, each new case was analysed anew. During the analysis of other cases when inevitably the analysis of the first case will influence the other, the current researchers denoted the importance of openness upon every analysis to allow emergence of new themes from different cases. Moreover, the researchers considered any similarities and/or differences between participants and any themes which are exclusive to a particular individual. This provides an indication of the nature of the variation across different cases (Howitt, 2016).

Step 5: Analysis write-up. Upon writing, the report included all of the themes which the researchers denoted as important in the analysis. The researchers took the prevalence of

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS data into account, at the same time providing richness of the extracts from the transcripts (Frost, 2011). The themes were carefully described and illustrated with exact quotes extracted from the interview transcripts. Further interpretation of the themes was done to make sense of what the participants said. Discussion were proceeded by examining relationships between the identified themes and existing past literatures with similar research interests.

Mixed Methods Data Analysis

Integration was conducted by connecting the results from quantitative survey and qualitative interview and matching the domains across the survey items and qualitative interview questions. Both results were then merged, interpreted, and presented through the discussion (Creswell, 2015). The results were explicitly merged through a side-by-side comparison to evaluate for confirmation, expansion, or discordance between the two data sets (Fetters, Curry, & Creswell, 2013). Confirmation of data is to determine whether both types of data reinforce the results from one another. Expansion enables the researcher to expand insights of HRQOL by addressing significant aspects when two data sets diverge.

Discordance occurs when the results from quantitative survey and qualitative interview were inconsistent and contradict with one another (Fetters et al., 2013). Triangulation was also involved to include comparison of results from past literatures conducted in the similar population of interest.

Chapter IV: Results and Findings

Quantitative Survey

A total of 53 young cancer survivors had participated in this research, with a mean age of 29.30 years old (SD = 5.51). The data were comprised mostly by female respondents (71.70%) where there were only 15 male respondents (28.30%). The distribution among ethnicity were balance between Malay and Chinese respondents, with 21 participants each (39.60%), 10 Indians (18.90%), and one Sikh (1.90%). Moreover, most of the respondents had received a highest level of education of a Bachelor's degree (47.20%), Most respondents were diagnosed with breast cancer (26.40%), while lymphoma came in second (22.60%). The mean time since recovery is 4.45 years (SD = 3.91). Other demographical and clinical information were tabulated in Table 1.

Table 1

Demographic and Clinical Characteristics of Quantitative Survey Respondents

Baseline characteristics	n	%
Gender		
Male	15	28.3
Female	38	71.7
Ethnicity		
Malay	21	39.6
Chinese	21	39.6
Indian	10	18.9
Others	1	1.9
Marital status		
Unmarried	33	62.3

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Married	18	34.0
Divorced	2	3.8
Highest level of education		
Secondary education	7	13.2
Pre-university programs	5	9.4
Diploma	5	9.4
Bachelor's degree	25	47.2
Master's degree	9	17.0
Doctorate degree	2	3.8
Status of employment		
Unemployed/housewife/househusband	7	13.2
Full-time	34	64.2
Part-time	2	3.8
Student	10	18.9
Monthly income (RM)		
< 1,000	5	9.4
1,001 - 3,000	20	37.7
3,001 – 5,000	19	35.8
> 5,000	9	17.0
Living arrangement		
Living alone	10	18.9
Living with family	30	56.6
Living with romantic partner	13	24.5

Cancer type

Breast cancer	14	26.4
Colorectal cancer	1	1.9
Lung cancer	3	5.7
Lymphoma	12	22.6
Nasopharyngeal cancer	2	3.8
Leukaemia	5	9.4
Cervical cancer	3	5.7
Liver cancer	1	1.9
Ovarian cancer	2	3.8
Thyroid cancer	4	7.5
Others	7	13.2
Cancer stage		
Stage I	18	34.0
Stage II	20	37.7
Stage III	8	15.1
Stage IV	3	5.7
Not staged	4	7.5

Correlation between time since recovery and HRQOL. In efforts to examine the correlation between the time since recovery and the level of HRQOL as perceived by young adult cancer survivors, a Pearson product-moment correlation test was conducted. In accordance to the Cohen's rule of thumb as guideline for the strength of relationship, the result showed a weak positive correlation between the time since recovery and the HRQOL as perceived by young cancer survivors, with r < .1. Moreover, the correlation was not statistically significant, with p > .05. The result was tabulated at Table. Hence, the null

hypothesis stating that the time since recovery is not positively correlated with the HRQOL as perceived by young adult cancer survivors was rejected.

Table 2

Descriptive Statistics and Correlation Between Time Since Recovery and HRQOL

	Variable	n	М	SD	1	2	3	4	5	6	7
1.	Time since	53	4.45	3.90	1						
	recovery										
2.	Physical well-	53	3.61	1.14	.20	1					
	being										
3.	Social well-	53	3.46	0.90	06	.63	1				
	being										
4.	Relationship	53	3.89	0.93	16	.28	.32	1			
	with doctor										
5.	Emotional well-	53	3.37	1.06	.19	.78	.71	.48	1		
	being										
6.	Functional	53	3.54	1.18	.09	.80	.79	.45	.83	1	
	well-being										
7.	Overall	53	3.57	0.87	.07	.86	.83	.59	.92	.94	1
	HRQOL										

Difference between level of education and HRQOL. As the level of education is a non-parametric measure with more than one group mean, while the HRQOL is a parametric measure, a one-way analysis of variance was conducted to determine the difference between the education level and the level of HRQOL as perceived by young adult cancer survivors.

The statistical analysis showed a significant difference between level of education and the HRQOL as perceived by young cancer survivors (p < .001). The significance difference then leads to the commencement of a post hoc test to determine which group(s) were showing significant difference. As a result, young cancer survivors with a Bachelor's degree (p = .01) or Master's degree (p = .03) showed a significant difference in HRQOL as compared to those who stopped pursuing their education after getting a Diploma and those who graduated with a Doctorate degree. Moreover, an effect size of educational level on HRQOL was calculated using Eta square, η^2 , resulting in a large effect size of 30% variance in the HRQOL as perceived by young cancer survivors was explained by their educational level. Hence, the null hypothesis stating that no difference between the level of education and the HRQOL as perceived by young adult cancer survivors was rejected.

Table 3

Descriptive Statistics and One-Way Analysis of Variance on Level of Education and HRQOL

Measure	n	M	SD	F	sig-F
Highest level of education				4.03	.004
Secondary education	7	2.69	0.36		
Pre-university programs	5	2.90	0.66		
Diploma	5	3.33	0.85		
Bachelor's degree	25	3.82	0.86		
Master's degree	9	3.92	0.75		
Doctorate degree	2	4.33	0.26		
Total	53	3.57	0.87		

Difference between genders and HRQOL. An independent-samples *t*-test was conducted to test the difference in HRQOL between males and females. A Levene's test for

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS homogeneity of variance for HRQOL was not significant at .05 (F = .220, p > .05), therefore assumption of unequal variances was conducted. As depicted in Table 4, there was no significant difference, t(53) = -1.551, p = .641. Mean HRQOL score for females (M = 3.69, SD = .84) was slightly higher than mean score for males (M = 3.27, SD = .90). The effect size (d) was .66, indicating a medium effect. The results support the conclusion that HRQOL

Table 4

Descriptive Statistics and Independent Sample t-test on Genders and HRQOL

between males and females was not significantly different.

Variable	n	М	SD	t	p
Gender					
Male	15	3.27	0.90	-1.55	.64
Female	38	3.69	0.84		

Qualitative Interview

Five (5) young adult cancer survivors participated in the interview; all of them were females. The mean age of the respondents were 27.8 ± 3.4 years, while the mean time since completion of treatment is 4.32 ± 5.65 years, with the earliest since 2004 and latest at October 2019. The demographics of the respondent were tabulated in Table 5.

Table 5

Demographic and Clinical Characteristics of Qualitative Interview Respondents

Respondent	Age	Ethnicity	Highest level of education	Cancer type	Cancer	Time since recovery (years)
R1	23	Chinese	Bachelor's degree	Lymphoma	Stage II	1.75
R2	29	Malay	Bachelor's degree	Breast cancer	Stage II	1.00
R3	32	Indian	Master's degree	Lymphoma	Stage III	5.08
R4	29	Indian	Master's degree	Breast cancer	Stage IV	0
R5	26	Chinese	Bachelor's degree	Leukaemia	Not staged	13.83

The representation of the current result is based on six (6) main themes: Cancer as a traumatic experience; finding the positivity in cancer; hardships in survivorship; improvement in quality of life; social relationships; and life after cancer. Subthemes were also developed in better describing the experience of the respondents. The themes were summarized in Table 6.

Table 6
Summary of Themes and Subthemes

Themes and subthemes	Example quotes
Cancer as a traumatic experience	
Reduction on physical	" after finishing treatments, even now, I can feel
functioning	tired easily it's like what we call our body is
	crashing. It's like totally crashing for no reason, like
	you weren't (I wasn't) working out or anything, it's
	just crashing" (Leukaemia survivor, age 26)
Psychological disturbances	" I started getting depression again when I was
	diagnosed. And I have suicidal tendencies last year,
	because I was on a new medication and it was very
	tough. Everything was very overwhelming"
	(Breast cancer survivor, age 29, stage II)
Fear of infection	" when I took the train to work, I am so paranoid
	about germs that I try not to touch the handle. And I
	over-carry hand sanitizers, in case I have to hold (the
	handle)." (Lymphoma survivor, age 32)
Alteration in dietary patterns	" I will be very picky about the food, but we didn't
	really have much choice because we need to eat very
	healthy food. So, I will force myself to eat."
	(Lymphoma survivor, age 23)
Interference with academic	"One bad thing was because I have to miss school I
pathway	stopped school for 2 years." (Leukaemia survivor, age
	26)

Lack of services and social

awareness on cancer

"I wish that I had it (cancer support group) that time.

So maybe if I have the support group at that time, I

don't have to go through that social awkwardness."

(Leukaemia survivor, age 26)

Finding the positivity in cancer

Acceptance

"Throughout the cancer journey, I made it a point that

I accept my diagnosis as soon as I got it. I think a lot

of cancer patients have that denial phase, that's why

they are quite down." (Breast cancer survivor, age 29,

stage II)

The pros and cons of a chemo

port

"It's not that pain as compared to (the drug) straight

away inject to my hand." (Lymphoma survivor, age

23)

Distraction as a method for

emotional suppression

"It was just me talking to my family, trying to distract

my mind off things, like trying to watch TV and

listening to music." (Lymphoma survivor, age 32)

Hardship in survivorship

Social stigmatization

"The moment you go out, and you get stared at."

(Leukaemia survivor, age 26)

Fear of cancer recurrence

"There is just no guarantee, you might still get cancer,

and it even might be a different kind of cancer."

(Breast cancer survivor, age 29, stage II)

Barriers in future prospects

"They (employers) don't actually ask me about my

qualification or my skills, the cancer is the first thing

they go though. It's like everything about my skills

doesn't matter." (Breast cancer survivor, age 29, stage

II)

Inability to adapt to changes "Like you think everything is supposed to go back to

the way it was, but it's not. And you don't quite feel

like yourself ... we tend to beat ourselves up a lot

when it comes to this." (Breast cancer survivor, age

29, stage II)

Improvement in quality of life

Solution-focused towards "... if I focus so much on the problem, it is not able to

survival solve the problem. So, I really need to start figuring

out the ways to fix the problem. So, I started focusing

more on the solutions." (Breast cancer survivor, age

29, stage II)

Change in personal lifestyle "I do a bit of yoga. I try to kind of keep a bit active."

(Breast cancer survivor, age 29, stage IV)

Healthy working environment "It's considered lucky to have them (the colleagues) at

work." (Lymphoma survivor, age 23)

Intimacy and child-bearing "My husband also took turn to bring me to the

hospital, but that time we weren't married yet, and yet

he was so supportive also." (Lymphoma survivor, age

32)

Social relationships

A mother's love in "When I go for any appointments, my mom will be

unconditional there for me. so, I don't really feel alone because there

Assurance from medical

professionals

are people that came along with me and accompany
me." (Lymphoma survivor, age 23)
"I know it before the whole treatment started, and I
knew that this could happen so that was my mental

preparation." (Lymphoma survivor, age 32)

Theme 1: Cancer as a traumatic experience. Since the diagnosis of cancer, the process has been traumatic due to the overwhelming emergence of negative aspects during the treatment. Respondents had reported that the most painful treatment of all was chemotherapy, where the side effects from the treatment were the most significant, including physical pain, hair loss, tiredness, and loss of appetite. These side effects had resulted in a change in their lifestyle, and some effects even persisted until their survivorship.

Reduction in physical functioning. This subtheme revolves around the negative physical aspects as perceived by the respondents in which had significantly affected their quality of life. Physical pain appeared to be the most significant factor which affects the quality of life among the respondents, with all five (5) respondents reported that they have physical pain during their treatments using chemotherapy.

R1: "... when I feel the pain, it was very uncomfortable and I feel like I don't want to go for this (chemotherapy) anymore ..."

R3: "... when they (the chemotherapy drugs) go in to my body, it hurts..."

These survivors were also reminded by the time when their daily life functioning was affected due to the reduced energy level after every treatment session. They were experiencing fatigue and unable to accomplish daily tasks or any leisure activities. They took more rests than usual in result of the reduce energy level.

R5: "... after finishing treatments, even now, I can feel tired easily ... it's like what we call our body is crashing. It's like totally crashing for no reason, like you weren't (I wasn't) working out or anything, it's just crashing ..."

Although cancer survivors reported a significant reduction in their energy level after their treatments, they experienced improvements and regain much more energy to function better over the years. Based on the responses, survivors who lived more than 3 years since their last treatment reported that they felt less lethargic as compared to before; even though still experiencing it once in a while, but was greatly improved.

R3: "... I felt much better actually, of course it is still there, but I definitely felt better ..."

Survivors who had gone through surgery as one of the cancer treatments were experiencing much greater disturbances on their daily functioning, on top of the side effects from chemotherapy. Due to the surgical procedure, they were more cautious in their daily life activities and completing daily tasks was reported to be challenging as well.

R2: "... I have to be careful because I did surgery and I'm at risk of lymphedema, so I'm unable to carry anything too heavy. Sometimes I get tightness in my arm. I have to make sure that I do lymphatic massages and that is a part of a challenge as well, because I do labour-intensive work ..."

At times, cancer treatments also result in comorbidities which caused further disturbances to the functionality of cancer survivors.

R2: "... I have gotten stuffs that I haven't gotten before I was diagnosed. For example, I have very bad sinus and very severe migraines. When it gets really bad, I'm unable to work, I'm unable to go to work ..."

Psychological disturbances. As the main theme may imply, cancer is a traumatic experience that leaves a psychological scar on many cancer survivors, even years after they

had completed their treatments. Stress has been inevitable among cancer survivors, especially the stress they experienced when they were diagnosed with cancer where one survivor exhibited feelings of guilt and self-blame upon knowing her diagnosis.

R5: "... I was a bit confused, and I kind of asked myself 'Was it something that I did? Where did I do wrong?' ..."

Treating cancer is not cheap, despite the advancement of technologies, cancer treatments may be a burden for many cancer survivors who are still under treatments. This financial burden resulted in an increasing level of stress.

R4: "... it also affects your finances, especially when your financial situation is unable to afford it, because of the cancer medication being so expensive ..."

As cancer survivors were to endure the painful treatments, it caused anxieties among them as they were going for treatments. Some survivors were so overwhelmed by the severe anxiousness, they demonstrated aversive behavioural patterns, such as vomiting.

R3: "... I didn't have vomiting after the chemotherapy like other patients, but I did get vomiting every time I reach the hospital. I think that was more in my brain other than the feeling of vomiting because of the chemotherapy itself; it's more like me not wanting to be there subconsciously. And the medication given by the hospital was great in controlling my nausea so I wasn't vomiting, other than the time I reached the hospital ..."

Social support was reported to be an important component for many cancer survivors, regardless of when they were under treatment or during their survivorship. However, some survivors may experience loneliness, especially when they were disconnected from the members of the society due to their illness which they were not responsible for. For example, a leukaemia survivor who was forced to stop school because of her treatment experienced social isolation from her friends since her diagnosis, and quoted:

R5: "... I don't really have friends that time ..."

Interviewer: "But before you stopped school, I believe you have some friends in school, right?

R5: "Yea."

Interviewer: "Did they contact you during your treatments?"

R5: "No."

Depression was common among cancer survivors as well, mainly due to the accumulation of side effects from treatments and the negative aspects experienced by these survivors during their treatment. The unresolved depression eventually leads to suicidal ideation as reported by two survivors.

R2: "... I started getting depression again when I was diagnosed. And I have suicidal tendencies last year, because I was on a new medication and it was very tough.

Everything was very overwhelming ..."

R4: "... I felt tired and I felt like not being able to pursue life and live the normal life ..."

Fear of infections. Chemotherapy is a treatment which infuse drugs into the bloodstream, killing cancerous cells in the body. However, such procedure affects the healthy cells in the body as well, especially white blood cells. This results in a weaker than usual immune system. Hence, many cancer survivors were living their life in fear of infections.

R1: "... I can't say I'm fully recovered because I still have the chance to fall sick easily; my body is not as strong as compared to before I had cancer ..."

Moreover, because of this fear of infections, survivors were forced to avoid large crowds that may increase the risk of contaminating with bacteria, resulting in lesser social interaction.

R5: "... my family were more cautious, so I don't really go out much. In the sense that, even if I go to public places or to a mall, I go when it just opened or when it's just about to close, because it has the least number of people. So that I can stay away from human interaction as much. I mean the fear of transmission of disease from other people."

Some even exhibited compulsive behaviour because of the anxiety.

R4: "... when I took the train to work, I am so paranoid about germs that I try not to touch the handle. And I over-carry hand sanitizers, in case I have to hold (the handle)."

Alteration in dietary patterns. Loss of appetite was significant in most of the cancer survivors as well. As a side effect of treatments, survivors find it difficult to adjust to the change in dietary patterns, especially when survivors were to shift from the strongly-flavoured Malaysian diet to healthy one, which were usually tasteless.

R1: "... I will be very picky about the food, but we didn't really have much choice because we need to eat very healthy food. So, I will force myself to eat."

Things were more difficult for survivors who had to undergo radiotherapy concurrently with chemotherapy.

R3: "... I just finished my radiotherapy, so it affects my food intake as well ... I wasn't able to eat properly, even swallowing things was really difficult. My food intake was really low."

Interference with academic pathway. This subtheme was considered unique in this current study, because the sample within this age range included survivors who were studying when they got diagnosed. Hence, their academic was affected during their process of recovery. Cancer survivors were forced to stop school and focused on recovering from the disease.

R1: "... I was still studying when I got cancer, so I need to delay (my studies) ..."

R3: "When I was diagnosed, I was in my final year of my university, so it was really bad. I have to extend because I was going to hospitals frequently and I couldn't go to class."

R5: "One bad thing was because I have to miss school ... I stopped school for 2 years."

Despite the academic setbacks and socially isolated from school, positivity and acceptance of the setbacks enables these survivors to manage these adjustments. They prioritized the importance of health more, as compared the importance of their education.

R1: "... that time when comparing the disease and study, of course health is more important. So, you don't have a choice, you just need to stop studying and try to recover as fast as possible.

R3: "At that time it was more like I want to stay alive ... I don't want to die."

R5: "...my parents thought it's not worth risking my health for school."

Lack of services and social awareness on cancer. Cancer survivors were usually dissatisfied with the available services provided for cancer survivors, such as alternative treatments for the side effects and the availability of cancer support groups.

R2: "I haven't really found a-size-fits-all method for my low energy level situation ... it only helps for a very short period of time."

R5: "I wish that I had it (cancer support group) that time. So maybe if I have the support group at that time, I don't have to go through that social awkwardness."

Cancer awareness is essential in the prevention and early detection of cancer.

However, the lack of this survivor's awareness had led to the late detection of her cancer.

R1: "... during Form 1, I started to have red dots whenever I feel very hot and I feel very itchy. Doctor actually told me that is the symptom already, but no one knows."

Cancer survivors also hoped for the society to acknowledge on their disease and be more socially aware about their difficulties.

R2: "I think sometimes people forget that even when we are done with treatments, we still go through a lot."

R3: "People don't really know what I was going through."

Theme 2: Finding the positivity in cancer. Despite the difficulties throughout the treatments, cancer survivors did manage to motivate themselves to complete the treatments through positivity and optimism.

Acceptance. Most survivors reported that they accepted their illness as soon as they were diagnosed with the disease. They also reported that there were more accepting towards their illness as compared to their friends and family. The acceptance of the illness was the key factor which caused a greater level of motivation and is essential to drive them in completing their treatments.

R2: "Throughout the cancer journey, I made it a point that I accept my diagnosis as soon as I got it. I think a lot of cancer patients have that denial phase, that's why they are quite down."

Instead of denying their disease, survivors reacted to it with an open mind and restrain themselves from overwhelming, negative thoughts. They do not question the existence of the disease nor the reason for why the disease had affected them. They motivate themselves through the treatment by self-empowerment. The high level of determination was observed as this survivor shared how she motivated herself to contain her pain and completed her treatments.

R1: "... I won't say things like 'Why I need to go through this? Why is it so painful?'.

I try not to say these negative things but then I need to tell myself that I can do it.

Every time I go (to the treatments), I know it's very painful, but then I still tell myself that last time I can do it then this time I also can lah"

The pros and cons of a chemo port. A chemo port is a medical aid inserted near the chest of the patients which facilitate the infusion of chemotherapy drugs. The insertion of a chemo port reduces the pain from the treatment itself, as reported by most of the survivors.

R1: "It's not that pain as compared to (the drug) straight away inject to my hand."

On the other hand, inserting a chemo port did raise some other issues, such as disturbance on certain daily activities. With the chemo port inserted, a survivor reported that she was unable to do certain activities, and have to request help from people which she felt uncomfortable in doing so.

R2: "I have a chemo port and I cannot carry heavy thing, so I'm not used to having to wait for people to come and help to do certain things. That makes it very frustrating sometimes."

Moreover, the presence of a chemo port affected a survivor's physical appearance where she chose her daily attire to cover up the chemo port, in efforts to reduce social stigmatization. The survivor also further explained that her intention of covering the chemo port with uncomfortable clothes was to prevent further infection on the port.

R1: "I will cover it. Because I don't want to have people looking at me and think 'What is that weird thing?' ... sometimes I'm scared because of the infection (at the chemo port)."

Distraction as a method for emotional suppression. As survivors were overwhelmed by negative thoughts and emotions, most of them chose to suppress those feelings through distraction, either it is through entertainment or to avoid hospital settings. Although the suppression of feelings may not be an effective method in solving the emotional issue, but survivors reported them to be helpful at times when they were emotionally disturbed.

R3: "It was just me talking to my family, trying to distract my mind off things, like trying to watch TV and listening to music."

R2: "Yes, it is a distraction actually. It helps to manage the stress and the anxiety."

However, as the suppressed feelings were not fully resolved, it may result in an overly expressed feelings in the form of catharsis, as described by one survivor.

R4: "... I feel very frustrated ... I will cry, scream, or shout."

Theme 3: Hardship in survivorship. Unfortunately, the negative aspects of cancer did not just diminish even though these individuals completed their treatments; the side effect from treatment persisted until their survivorship. Hence, this theme addressed the negative experience of cancer survivors during their survivorship.

Social stigmatization. As harsh as it may seem, members of the society discriminate against those who were sick. The loss of hair, the presence of a chemo port, and the fact that people know these survivors had cancer before created a sense of stigmatization by the society.

R3: "When you don't have hair, people look at you; although they might not ask you, but they look at you."

R5: "The moment you go out, and you get stared at."

This stigmatization eventually leads to a decline in self-confidence when interacting with members of the society.

R5: "... I feel that they were judging me or being sympathetic towards me. it made me feel very low. I don't know, you just have lower confidence to socialize."

At times, cancer survivors were treated in ways that is insensitive. Survivors were dissatisfied when people treated them as a cancer patient, they wanted to be treated as equal as everyone else.

R2: "... they just feel like 'Okay, I'm just another patient, they (the doctors) are just going to treat me like any other patients."

Fear of cancer recurrence. The fear of cancer recurrence has been one of the sources of cancer survivors' anxiousness and five (5) of the survivors displayed such anxiety in their responses.

R2: "... it's also that the anxiety that comes from the possibility that the cancer coming back."

R3: "There is just no guarantee, you might still get cancer, and it even might be a different kind of cancer."

This fear had sometime caused severe anxieties where the survivor was excessively self-conscious about her health.

R3: "... even if it's something small like if I have fever, I get too worried."

Barriers in future career prospects. Being diagnosed with cancer has affected the survivors when they were looking for a placement in a company. Some survivors reported that they were unable to work in the career which they were interested in because of workplace discrimination. As members of the society had a constant perception that cancer patients were unable to work productively, they judge their ability to work not on the qualifications but on the severity of their illness and the possibility of the cancer recurrence.

R2: "They (employers) don't actually ask me about my qualification or my skills, the cancer is the first thing they go though. It's like everything about my skills doesn't matter."

Also, a cancer survivor had to give up her job just because the nature of the job may increase the risk of the cancer recurrence, forcing them to switch jobs. This survivor also portrayed some grief in her career restriction because of the disease. Her tone was softer while she had a long pause before sharing about her experience.

R1: "... during that 2 months I almost every day work until 12am, and early morning
I need to wake up at 5am ... I will say it will have a higher chance to fall sick again ...
(long pause) ... if I didn't get the disease, then maybe I will continue with my previous
job,"

Inability to adapt to changes. Some respondents still regress at their time before they got cancer and was wanting to go back to how they used to be, rather than adapting to the changes and focusing on the future. It resulted in frustration and disappointment.

R2: "Like you think everything is supposed to go back to the way it was, but it's not.

And you don't quite feel like yourself ... we tend to beat ourselves up a lot when it

comes to this."

Theme 4: Improvement in quality of life. This theme addressed the efforts made by these cancer survivors to adjust to their survivorship and made improvements in terms of their quality of life.

Solution-focused towards survival. Although they regress on their health status, cancer survivors still continued to focus on how to solve the problem instead of having the negative aspects taking over them. They adapted a solution-focused mindset and made efforts to live a better life.

R2: "... if I focus so much on the problem, it is not able to solve the problem. So, I really need to start figuring out the ways to fix the problem. So, I started focusing more on the solutions."

With that solution-focus mindset, the respondent appeared to be an independent and strong-willed survivor who wanted to make a change based on her own capabilities. This personality was reflected on her enthusiasm in building her own career and not relying on situations that happen by "chance".

R2: "I managed my expectations in the sense I'm not waiting for a miracle to happen, so I was just trying my best and do whatever I can.

Change in personal lifestyle. Although previously had mentioned that some survivors were lethargic and unable to perform much physical activities, some become more physically active for them to feel better. They reported to regain more energy though physical exercises, such as dancing, swimming, and doing yoga.

R3: "I'm able to do physical activity like walking, carrying things, or like swimming.

I feel healthier."

R4: "I do a bit of yoga. I try to kind of keep a bit active."

Survivors also reported an increase in positive mood after exercising, especially when doing activities that they enjoyed doing.

R4: "So, when you work out, or when you do things that you love, your body releases a certain happy hormone. And so, because of that you will be happy doing it."

However, these survivors were unable to perform these activities for a long period of time as they felt more tired after those activities; therefore, they do it in moderation.

R2: "... because sometimes I exercise, I get too tired to the point where I cannot sleep. So, I find the balance is quite tough, because certain times I works, but certain times it doesn't."

Survivors also reported having healthier diets as compared to before. They started cooking food at home instead of having meals from restaurants. Their diets consist mostly on fruits and vegetables. Although they still eat out occasionally, but most of their food were from home.

R3: "I try not to eat out, I eat at home with food that I make myself, for my family."

R1: "... I eat this (vegetables) and eat lesser meat. And then I try not to eat canned food and those fried, oily food."

A cancer survivor took up a new hobby which eventually became her career now.

While she was staying at home during her treatments, she started baking at home as a leisure activity. Her interest has now become her business, indicating an increased level of functionality despite being confined at home.

R2: "... I actually run my own baking business. I only picked up baking when I was going through chemotherapy ..."

Interestingly, a change of living environment was effective in improving the mental states of survivors as well. A survivor constantly stayed over at her sister's place and had short trips away from home, and it enlightened her mood.

R2: "... a change of environment for me was a huge part of recovery, because it's a different environment, and sometimes staying in on place kind of made me very depressing."

Healthy working environment. Despite having some employers discriminating against cancer survivors, some survivors managed to get a placement in a company where they were able to gain functionality in their career. Moreover, survivors who obtained a placement reported healthier working environment where discrimination was minimal. They had understanding superiors and colleagues as well, which improved their quality of life at work.

R1: "It's considered lucky to have them (the colleagues) at work."

R2: "... my workplace is very understanding."

Although sometimes when the side effects of treatments were severe and the survivors had to take rests from work, they reported they will continue to contribute as much as they could right after they took their necessary rests. This indicated a sense of responsibility in their work.

R4; "... they (the superiors) understand that when I come back from work, I give my 100% and I complete all my work, and try for the betterment of the company."

Intimacy and child-bearing. Throughout the recovery process, intimacy with romantic partners were reported to increase survivors' acceptance and greater motivation to complete the treatment. This is because they were able to share more of their emotions as compared to other people, such as their friends.

R2: "When I'm feeling sad or frustrated, then I would talk to my friends about it, or even my husband. With my husband, I think we can talk about more intimate things."

Survivors reported their romantic partners were possessing characteristics which made them felt understood and autonomous during their treatment. Characteristics such as non-judgemental, openness, and supportive were reported to be important characteristics. The survivors were not married yet when they were undergoing their treatments, but now happily married.

- R2: "He actually at that time, we were not married yet. He was not judgemental at all, and he didn't push me to make decision, so I can openly tell him how I'm feeling or how I feel about certain things."
- R3: "My husband also took turn to bring me to the hospital, but that time we weren't married yet, and yet he was so supportive also."

Another interesting factor that improved the quality of life among cancer survivors was child-bearing. Among the interviewed survivors, there was one survivor who experienced infertility as a complication from the treatment. Her period stopped and was unable to bear child in the future. However, she still managed to bear a child after treatment and marriage. Her child was the source of her regained functionality as her improved daily functioning revolves around him.

R3: "I cook for my son as much as I can, because I want him to eat well. I like him to eat nutritional food ... swimming is good because my son loves the water. So, when we go to the pool, he gets to play as well."

Theme 5: Social relationships. Social support was found to be essential in helping survivors to promote their well-being during survivorship, especially with their emotional well-being. This theme explains how cancer survivors were empowered through interactions with members of the society.

A mother's love is unconditional. Among the members of the society, mothers had been acknowledged the most as a supportive figure for cancer survivors. The survivors reported that their mother was there for them since the beginning of their diagnosis, through their treatments, and even during survivorship. They described how supportive their mother was towards their illness, especially in providing physical accompaniment and necessary cares. The presence of their mother being there with them reduced their feelings of loneliness.

R1: "When I go for any appointments, my mom will be there for me. so, I don't really feel alone because there are people that came along with me and accompany me."

R3: "My mom used to cook things according to what I can and cannot eat, because of a lot of limitation."

As mothers accompanied these survivors for a long period of time, they were worried about the health of the survivors. They were able to notice minor changes in physical appearance and started to get worried about them.

R1: "... when I come back from work, I felt that my face become pale, then she (her mother) will straight away ask, 'You got fever or not? Got feel where very pain or not?' and she will straight bring me to hospital, even in midnight ..."

In the presence of their mother, survivors were able to express their feelings openly and interact with her whenever they were in the treatments.

R1: "... I will sometimes talk with my mom about it during my treatment."

However, some survivors chose not to share her emotional thoughts with their mother because they were afraid it may cause an emotional burden for her as she may not be able to handle it.

R4: "I try not to share my emotional disturbances with her. Because it would bring her more stress."

Assurance from the medical professionals. Medical professionals were considered someone who the cancer survivors can rely on, since these professionals are more knowledgeable than the survivors themselves about their illness. Survivors displayed some form of reliance on their doctors when it comes to their disease.

R1: "The doctor told us to go for the test then we just go for it."

R2: "I was very close to my nurses and doctors, so it made me more comfortable in the hospital setting."

Hence, the sense of assurance portrayed by these individuals were important for cancer survivors. Medical professionals were to provide as much information as possible for their patients so that they could be mentally prepared for what is about to happen. It reduces the anxieties among cancer survivors; they reported to be more relieved after being given with information on their disease.

R1: "So, the doctors said that I can fully recover after 6 months, so I will be more relieved after that."

R3: "I know it before the whole treatment started, and I knew that this could happen ... so that was my mental preparation."

The sense of assurance from doctors enabled survivors to seek help from them whenever they found some abnormalities with their body, which further reduced their level of anxiety about their cancer recurrence.

R2: "So, I would actually contact her (doctor) and then she would advise me to monitor it, and if the pain still persists then come and see her. So that actually helps to manage the worrying."

A survivor also reported that doctors who were supportive and non-judgemental gave them the most assurance and faith.

R2: "...doctor that would be comfortable for me would be somebody who is not judgemental, that's the number one characteristic. Another thing is not to force me to make my decision."

Converging Data

Upon converging both data from quantitative surveys and qualitative interviews, the current research were to explore the factors that influence the perception of HRQOL as perceived by young adult cancer survivors. Exploratory interviews enabled researchers to understand the cause of young cancer survivors' change in HRQOL throughout their survivorship, including physical functioning, social relationships, assurance from healthcare providers, psychological growth, and their ability to adapt to functional changes. However, researchers then discovered the cause of these changes is based on the component of self-concept. Personality and strong self-concept were acknowledged to be the sources of young cancer survivors' improvements in their HRQOL, specifically optimism and hopefulness.

Optimism.

R1: "There are a lot of people going through the same thing like me, and if they can do it, of course I can do it too."

R2: "... I have that mindset of trying to live day by day..."

R3: "I want to show people that, just because I have cancer it doesn't mean that things are over."

R4: "I always say that, without these treatments, I can't be alive."

R5: "I think I'm positive, like 'I can do this' and look forward for the next day..."

Cancer treatments are known to be painful and difficult for cancer patients to go through, especially when they are already facing death upon their diagnosis. However, it was discovered that although challenging, young cancer survivors were optimistic in facing their treatments and hardships in life. This can be seen through the interview where these young survivors possess positivity in their personality traits, as observed through their willingness to share their experiences which was traumatic. Being able to take the first step and share their traumatic experiences with someone whom they were stranger of described their openness and enthusiasm in seeing cancer as another obstacle to break through, rather than regressing on their illness with negativity. Despite the challenges where R1 had to give up her dream job; R2 being discriminated during job employment; R3 living in permanent infertility; R4 with a stage 4 breast cancer relapse; and R5 lived in social isolation for 2 years, all 5 respondents exhibit significant recovery and achieved greater HRQOL by possessing optimism as their personality trait, as interpreted by the current researchers during he interview.

Hopefulness.

R1: "... if you don't have hope, you're giving up on everything."

R2: "... we (survivors) need to have something or someone to fight for."

R3: "The experience was traumatic at that time, but now I'm living with the memory of it, in hope for a better future."

R4: "... I always try to live in the present, but I want to continue living a normal life."

R5: "I want to survive, and look forward to the next thing that is going to happen and what I wanted to do in life."

Optimism was not only the factor which leads to an increased HRQOL among cancer survivors. As cancer survivors actually survived through cancer, in terms of completing

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS treatments and recovered, they were to face a continuous challenge during their survivorship. As reported in the previous section, young cancer survivors were to endure stigmatization from members of the society onto survivors' change in physical appearance (e.g. hair loss), barriers on their future career prospects, and their fear of the recurrence of the disease; yet, having hope is what motivated them to drive through. Young cancer survivors described them being hopeful in terms of having life goals to be achieved and to regain autonomy in the society. Interestingly, 3 out of 5 young cancer survivors reported that they were supportive to people who were less fortunate, such as volunteering in the Deaf Community Malaysia. They mentioned that they understand how people in need because they were once like them before, and were to give hope to people by supporting them. Hopefulness increases the functionality of young cancer patients as hope encouraged them to continue living life to the fullest, such as doing things that were once thought of but never fulfilled due to the diagnosis of cancer. One survivor explained that she was operating her own baking business as she learned baking skills and baked during her treatment when she was constantly staying at home. Being hopeful, she is to open up her own café in the near future and empower cancer patients by hiring them as her employees. Her hopeful personality had drove her to work in a café and learn skills needed for her to operate on her own in the future. Hence, hopefulness improves

cancer survivor's functionality.

Chapter V: Discussion and Conclusion

Discussion: Quantitative Survey

The impact of time. The study aimed to examine the correlation between the time since recovery and the level of HRQOL as perceived by young adult cancer survivors.

Through review on past literatures, the current researcher hypothesized that there is a positive correlation between time and HRQOL; however, the low significance level computed from the data led to the reduced confidence in supporting the hypothesis, although positive correlation was observed. With support from results in past literatures, the failure in supporting the hypothesis may largely due to the limitations in this current research.

As a result of the invasive treatment procedures, for example chemotherapy, its side effects were highly reported as factors for diminished HRQOL in long-term cancer survivors (Huang et al., 2013). However, such decrement in HRQOL was only observed within a year among survivors who achieved full recovery, as reported by Vindrine, Hoekstra-Weebers, Hoekstra, Tuinman, Marani, and Gritz (2010). Some studies also indicated that young cancer survivors may even fail to regain better quality of life up to 2 years since their recovery (Jörngården, Mattson, & von Essen, 2007; Larson, Mattson, & von Essen, 2010). Over time, survivors reported an increase in HRQOL (Jörngården et al., 2007; Larson et al., 2010), similarly found in the positive correlation between time since recovery and HRQOL in the current research. It was further discovered that the most significant increase of HRQOL were physical and mental scores (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013), indicating a positive relationship between HRQOL and post-traumatic growth. Cancer treatments usually result in great levels of post-traumatic growth among young adults affected by cancer, but it was also found to be a protective factor against the decrease of HRQOL over time. Over the years of survivorship, post-traumatic growth was reported to enhance greater development of positive perspectives towards the treatment and resulting in

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS stronger resilience in coping with difficulties during survivorship (Zeltzer et al., 2008). Hence, resilience was recognized as possessing a mediating effect on the increasing of HRQOL by promoting greater adjustment towards the side effects and changes in survivorship (Wu, Tsai, Liang, Liu, Jou, & Berry, 2015).

Interestingly, longitudinal studies discovered a decrease in HRQOL, particularly mental health scores (Ander et al., 2016; Vlachioti et al., 2016). Although this pattern was not observed in the current study due to the cross-sectional design used, several studies reporting this pattern in HRQOL decrement creates an alarming concern for health-care providers. This decrement in mental HRQOL may be largely due to the fear of cancer recurrence (Ferrell, Smith, Cullinane, & Melancon, 2003; Cozaru, Papari, & Sandu, 2014). The fear of recurrence influences various aspects of life among cancer survivors, including the cognitive and emotional aspects (Koch et al., 2014) where a high level of fear resulting in interference with daily functioning as well as reduced HRQOL during survivorship (Humphris & Ozakinci, 2008). Fear of recurrence was highly prevalent among cancer survivors (Koch, Jansen, Brenner, & Amdt, 2012) with between 33% to 96% of survivors reporting it as the most important concerns (Harris et al., 2009), there are still lacking of studies on long-term cancer survivors as well as clinical significance on instruments measuring the fear of recurrence within this population (Thewes, Butow, Zachariae, Christensen, Simard, & Gotay, 2012).

Although most long-term young cancer survivors from developed countries experience an increase in HRQOL, young cancer survivors living in Southeast Asia experienced otherwise, mostly in low- and middle-income countries (e.g. Malaysia). Cancer usually affects people living in these countries with worsening health status and loss of productivity (Kimman, Norman, Jan, Kingston, & Woodward, 2012). Poor health outcomes among young cancer survivors were significant barrier to daily functioning and career prospects (Islam, Dahlui, Majid, Nahar, Mohd Taib, & Su, 2014). The low HRQOL score

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS was then worsened alongside with physical inactivity and unhealthy dietary habits (Stewart & Wild, 2014), in which Malaysian young cancer survivors were actively practicing (Loh, Chew, & Lee, 2011; Vivien & Mohd Noor, 2013). Moreover, another possible explanation for the reduced HRQOL as reported in low- and middle-income countries may be a result of poor cancer awareness and the accessibility to healthcare services after recovery (Niksic, Rachet, Warburton, Wardle, Ramirex, & Forbes, 2015). People with low socioeconomic status usually face challenges in accessing necessary follow-up care during their survivorship and unable to discuss concerns with medical professionals (DiMartino, Birken, & Mayer, 2016). Hence, poor socioeconomic conditions were found to be predictors of impaired HRQOL and resulting in psychological distress among cancer survivors living under those conditions.

Level of education as a protective factor. Educational level was hypothesized to possess a significant difference in regards to HRQOL as perceived by young adult cancer survivors. Results from the current study supported the hypothesis, stating that young cancer survivors with a Bachelor's degree and Master's degree exhibit difference in HRQOL scores as compared to those with a highest academic accreditation of a Diploma certificate and those who are PhD holders.

Hartung and colleagues (2015) reported that among 164 survivors, those who acquired secondary school qualifications showed lower HRQOL in comparison with other survivors who received tertiary education. This pattern is similarly observed in other cancer-related cohort studies (Goldfarb et al., 2016; Zeltzer et al., 2008). However, physical HRQOL had a higher score among the domains of HRQOL as reported by cancer survivors with secondary education qualifications (Hartung et al., 2015). With only a qualification of a secondary education, young cancer survivors strived to meet psychosocial concerns, such as establishing personal identity, on top of difficulty in job employment and seeking for higher

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS education (Zeltzer et al., 2008). This increase of desire for socioeconomical needs affect psychological functioning as well as HRQOL in long-term young cancer survivors (Wallander & Koot, 2016). On the other hand, Malaysian adolescents who graduated only from secondary schools were found to have an increased resilience towards developmental challenges (Kuldas, Hashim, & Ismail, 2014), which the effect persisted to young adulthood as reported in students who successfully pursued their undergraduate studies in later years (Narayanan & Onn, 2016). The presence of resilience may be a predictor for higher levels of physical well-being among long-term young adult cancer survivors.

While young survivors with secondary education had greater physical HRQOL scores, survivors with a tertiary education reported to acquire greater levels in mental functioning in their HRQOL score (Hartung et al., 2015; Nolan, Krull, Gurney, Leisenring, Robinson, & Ness, 2014). Tertiary education not only provide greater job qualifications, but it also widens the knowledge of young adults on mental health (Gulliver, Griffiths, & Christensen, 2010) and strengthens their psychological well-being. As young adult cancer survivors were constantly reported to exhibit psychological concerns and anxiety (Goldfarb et al., 2016), the increased mental health literacy among university goers were able to improve their mental health status; leading the current researcher to predict the higher score of mental HRQOL among young adult cancer survivors. Furthermore, social support was found to be a significant predictor of positive mental health among undergraduates (Hefner & Eisenberg, 2009). However, young cancer survivors who received tertiary education did not report similar or higher level of social functioning in their perceived HRQOL in comparison with their mental HRQOL. This is further explored and explained that HRQOL measurements involved parent-child relationship within the measures of social well-being, in which was found poor in most undergraduates (Pizzolato & Hicklen, 2011; Wolf, Sax, & Harper, 2009), which is also found reported in the Malaysian context (Baharudin & Zulkefly, 2009; Mohd

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS Ishak, Md Yunus, Iskandar, 2010). Hence, the lack of involvement with parents in young tertiary-educated cancer survivors' daily interaction resulted in the higher level of mental well-being, but not in the social domain of HRQOL.

Lastly, results from the current study showed that young cancer survivors with a Doctorate degree qualification expressed a significant difference in HRQOL as compared to those with Bachelor's degree and Master's degree. Although there were lack of research exploring the correlation between specific educational level and HROOL (most categorized Bachelor's degree, Master's degree, and Doctorate degree qualifications as tertiary education; Nolan et al., 2016), the current research hypothesized the association between stress and low HRQOL among these survivors. The pursuit of a Doctorate degree usually resulted in high levels of stress and more mental health concerns than medical students (Toews et al., 1997), while the high level of stress caused significant long-term impact on the quality of life (Ogunsanya, Bamgbade, Thach, Sudhapalli, & Rascati, 2018). Hence, on top of the stress from cancer treatments, the long-term effect of stress from the post-graduate studies may worsen and leads to the decrease in HRQOL as perceived by these young cancer survivors. Moreover, this phenomenon can be further explained using the Maslow's Hierarchy of needs in which the motivation of one's behaviour to towards achieving different needs (Simons, Irwin, & Drinnien, 1987). In conditions where survivors with a Doctorate degree having their priority other than health itself, they were more empowered and concerned on their selfimage, leading to a need for self-actualization (Bilal, Doss, Cella, & Rogers, 2014). This may directly affect their physical consciousness, resulting in emotional distress if the needs were not achieved. However, due to the small sample size in this current study, the association may be less significant to be generalized in the larger population.

Gender differences. The current research also aimed to investigate the difference between males and females on their perceived HRQOL. As a result, there were no significant

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS difference between the two groups, which was contradicting to past literatures. Overall, females were reported to exhibit lower HRQOL scores as compared to their male counterparts (Husson et al., 2017; Harju, Roser, Deher, Michel, 2018), where similar pattern was found in the Malaysian context (Natrah, Ezat, Syed, Mohd Rizal, & Saperi, 2012). Female young survivors experienced lower social well-being as compared to males across cultures (Tremolada, Bonichini, Taverna, Basso, & Pillon, 2017; Puteh et al., 2013). This can be related to a great portion of females having high expectations in forming social relationships; however, they presented feelings of disappointment upon not being able to form healthy relationship with their peers (Brice et al., 2011). This pattern may be especially significant in the Asian cultural setting as Asians tend to emphasize on seeking relationships among peers for support (Schroevers & Teo, 2008). Moreover, physical functionality was significantly low among female cancer survivors (Natrah et al., 2012). Females reported greater symptoms of pain, and fatigue being the most relevant factor for decreased physical functioning among women (Ruste & Ngelangel, 2011) because of the more severe effect of treatments on women physically; thus, they were having more symptoms than males. Gender difference in HRQOL was also found in the emotional domains, where females were reported to be experiencing greater levels of depression (Harju et al., 2018). Such emotional disturbances usually arise from the concerns on physical appearance and questions on fertility (Nightingale et al., 2011).

However, the difference between genders on HRQOL scores may be contradictory in males who are minorities and facing financial difficulties. A study conducted on Latino men in Los Angeles reported that these men were experiencing greater levels of depressive symptoms and lower HRQOL as their female counterparts (Ritt-olson et al., 2018). It was hypothesized that being a minority in the United States may resulted in them receiving poorer post-cancer care and they were at distress at their inability to care for their families (Ritt-

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS olson et al., 2018). This may be similar in Malaysia as a middle-income country and poverty is part of the concerns for the future development of the country (Hatta & Ali, 2013). The results from past literatures and current research were contradictory, most probably due to the over representativeness of females in the sample, with 71.7% females comprising the total sample; thus, increasing response bias of the result.

Discussion: Qualitative Interview

At the age of between 18 to 39 years old, the diagnosis of cancer is not just a burden on their shoulders, but it is definitely a traumatic time during their development. Being diagnosed with cancer at this developmental stage may result in disruptions in these young adults' physical, social, as well as psychological development, potentially causing a decreased quality of life upon commencing treatments (Tai, Buchanan, Townsend, Fairley, Moore, & Richardson, 2012).

Reduction in physical functioning. Throughout the treatments, cancer survivors were reported to be less active as compared to before they started treatments, which is similarly reported in past literatures. Young adult cancer survivors carried out fewer physical activities, in comparison to their healthy peers and siblings (Phillips-Salimi & Andrykowski, 2013). As described from cancer survivors, their lack of physical activity was due to the reduced energy level after they underwent chemotherapy. As chemotherapy was reported to be a painful process throughout the whole treatment, survivors who went through chemotherapy took more rests than usual. The reduction of physical movements was significant in influencing the HRQOL among the cancer population (Demark-Wahnefried & Jones, 2008), this was observed through the description of survivors where they failed to achieve daily life functioning, such as working and attending classes in the university.

Although some survivors did portray a greater level of functioning, through leisure activities which they were interested in. In past literature, young adult cancer survivors were found to

possess high level of interests in participating in exercises and physical activity (Belanger, Plotnikoff, Clark, & Courneya, 2011a). Cancer survivors from the current study also expressed their interested in leisure activities, such as dancing and swimming; however, those activities were only done when the treatments were completed and they started to regain physical functioning. Moreover, in the case where cancer survivors who were physically active, they were actively receiving information on practicing healthy lifestyle and meeting the public health exercise guidelines as provided by the hospital (Belanger, Plotnikoff, Clark, & Courneya, 2012b). Unfortunately, there were no information on such services reported in the Malaysian context, which may constitute to the sedentary among young Malaysian cancer survivors; past literature, too, reported that at least 40% of patients were not informed about such services (Zebrack, 2008). In another study conducted by Murnane, Gough, Thompson, and Holland (2015), 85% of cancer survivors expressed a desire for information in promoting physical functioning, only 50% of them received such information. This lack of information contributed to the inactivity of cancer survivors, eventually reporting a lower HRQOL.

Furthermore, different cancer diagnosis and treatment may result in a barrier between young adult cancer survivors and physical activity (Warner et al., 2016). For example, a breast cancer survivor described the implantation of the chemo port prevented her from strenuous physical exercises in which she was to do labour-intensive work during that time. Moreover, her tumour-removal surgery done on her breast had resulted in pain in her other breast as well. A majority of breast cancer survivors experience mild to moderate levels of physical discomforts as a complication from the surgery on the breast, which affects the HRQOL of these survivors (Shin et al., 2017). The persistent physical symptoms include fatigue (Bower et al., 2006) and pain in the breast (Erikson, Pearson, Ganz, Adams, & Kahn, 2001). However, interventions done in efforts to promote physical activity among breast cancer survivors reported a significant reduction of fatigue (Hwang et al., 2008) while

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS increasing both emotional (Kim et al., 2011) and physical functioning (Lee, Yun, Park, Lee, Jung, & Noh, 2014). As survivors exercise, their functional capacity increases, together with the improvement of muscle efficiency (Dimeo, Rumberger, & Keul, 1998). The enhanced muscle efficiency then explains how survivors with greater physical activity are able to carry out daily tasks with less lethargic (Lucia, Earnest, & Perez, 2003).

As cancer survivors experience a reduced level of energy and sedentary, they also encounter a reduction on HRQOL in terms of social interactions; they isolate themselves at home in order to take more rests. Poor social relationships and social networks were associated with poorer health status, especially among patients with chronic illnesses such as cancer (Pinquart & Duberstein, 2010). Social isolation is the perception of lack of social support, and feeling a sense of loneliness and not belonging as a member of the society (Cornwell & Waite, 2009). Although this issue is a major concern until today, but these negative experiences are not fully explored and understood among this population (Howard et al., 2014). As experienced by a cancer survivor during the interview, she stopped school for 2 years when she was 10 years old because of the frequent visits to hospitals and she was too weak to attend school at that time. She reported herself being isolated from her friends and was lonely. Loneliness was commonly experienced by survivors of childhood cancer (Foley et al., 2006) and they face difficulty in social interaction when they reach adulthood (Gurney et al., 2009).

Social stigmatization. During the adolescent and young adult years, an individual identifies his or her sense of self by relating to others (Tindle, Denver, & Lilley, 2009). This sense of identity is formed through the interaction of the bio-psychosocial developmental changes that they experience through the years (Christie & Vincer, 2005). An experience of cancer changes an individual biologically and psychologically, whereby effects of treatments may result in bodily changes. Hair loss is the most notably changes that a cancer survivor will

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS experience if chemotherapy is part of the treatment plan, as described by the interview respondents as well as biological research (Arwert, Hoste, & Watt, 2012). Zebrack and Chesler (2001) reported that cancer survivors do possess health-related worries due to the change in physical appearance which further deteriorates their self-image upon facing members of the society. Social stigmatization refers to the attribute that members of the society made which results in a person (the one being stigmatized) feeling different from others and eventually being discredited by the society (Goffman, 1963). Stigmatization was a traumatic experience, as expressed by interviews respondents. They were anxious upon leaving the house and people stared at them; the survivors felt that they were being judged by their body appearance which is not part of the norm. They wore hats all the time when they went outdoors, catching even more attention along the way. Some were disturbed by the presence of the chemo port and were forced to wear clothes that they were uncomfortable with to cover up the chemo port from the sights of the public. Physical appearance has a strong impact on young adults' self-image, especially when now they were at their critical time on developing it (Fine, Haley, Gillbert, & Forth, 1993), and negative thoughts and feelings about their bodies leads to dissatisfaction with their own identity (Przezdziecki, Sherman, Baillie, Taylor, Foley, & Stalgis-Bilinski, 2013). Literature had also validated the result reporting that young adult cancer survivors did experience negative emotions related to their body image, together with perceived stigma from the society (Quinn, Goncalves, Sehovic, & Bowman, 2015).

With social stigmatization at bay, young survivors were gradually experiencing a disruption in their self-esteem upon interacting with members of the society, as reported by interview respondents. Ettinger and Heiney (1993) mentioned that changes in appearance caused psychological trauma for young cancer survivors, leading to a significant impact on their self-esteem. Low self-esteem is known as a risk factor for impaired HRQOL during

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS cancer survivorship (Rhee et al., 2014). Moreover, low self-esteem and body image concerns were obstacle for young survivors to develop close interpersonal relationships, further reducing their social well-being with members of the society (Clinton-McHarg, Carey, Sanson-Fisher, D'Este, & Shakeshaft, 2012). Respondents reported anxiety when they were anxious, but at the same time empowered by their friends who did not view them negatively. They reported greater social support from friends, resulting in greater friendship. As reported from a literature, it was found that survivors developed more positive relationships with others than before the disease, which is similar to the responses from young survivors (Mattsson, Lindgren, & von Essen, 2008). While social stigmatization leads to deprivation of HRQOL, empowerment from social support is associated with decreased levels of depression and anxiety (Corey, Haase, Azzouz, & Monahan, 2008).

Although social stigmatization may be a negative aspect influencing the perceived HRQOL, it might be a protective factor as well. A qualitative study on 7 young childhood cancer survivors reported that the emotional concerns that they had on their appearance allowed them to make it through with strength and a positive attitude toward life (Enskar & bertero, 2010). Similar to what was shared by the survivors, although they did exhibit symptoms of depression and anxiety, but they chose to look pass those negative judgements and live for who they are over the years. They reported better adjustments towards people when going outdoors, and also reported an improvement in social interaction with strangers after few years; they developed a positive self-concept within themselves and achieved post-traumatic growth. Quantitative research had found that more than 60% of young survivors reported positive change in their perspective of self over the years (Arpawong et al., 2013), and higher rates of happiness (Bitsko, Stern, Dillon, Russell, & Laver, 2008). Moreover, Arpawong and colleagues (2013) had also argued that post-traumatic growth is responsible for the positive effects on psychosocial functioning among cancer survivors.

Barriers in future career prospects. Being employed is beneficial in improving one's well-being and HRQOL (van Rijn, Carlier, Schuring, & Burdorf, 2016). Meanwhile, being sent off from the workforce involuntarily can result in negative effect on mental and physical health (Karsten & Moser, 2009), whereby the adverse effect is even more severe when occurring among people going through chronic illnesses, such as cancer (van Egmond, Duijts, Vermeulun, van der Beek, & Anema, 2015). Similarly reported by young survivors, they were confronted with employers judging their health status on their productivity at work instead of assessing their qualification and credibility; they were discriminated even before they were given an opportunity to showcase their qualification. Cancer survivors were usually found encountering a significant risk of unemployment (de Boer, Taskila, Ojajärvi, van Dijk, & Verbeek, 2009) and were less likely to be re-employed after treatments (Park, Park, & Kim, 2009), even in the Malaysian context (Tan et al., 2012). This leads to a reduced HRQOL with lower functionality score, as evidenced by Lee, Kim, Shin, Han, and Park (2015). Moreover, most survivors were highly motivated to return to work, as expressed through their high levels of functionality and determination for work, also similarly reported in a qualitative study on breast cancer survivors by Kennedy, Haslam, and Pryce (2007). Yet, they were still unable to be acknowledge as someone who are productive enough to work.

Despite of that, some survivors did manage to reserve a job placement. These survivors usually expressed greater level of HRQOL as described by how they were productive at work and the commitment they were able to provide for the company. Past literatures had concluded that survivors who return to work exhibit an extensive improvement in health as well as HRQOL, while those who became unemployed developed more severe physical and mental disturbances (van Rijn et al., 2016; Schuring, Robroek, Lingsma, & Burdorf, 2015). Survivors who were able to return to work or got employed, they reported that they were glad to be working in a healthy environment where their colleagues and

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS superiors were understanding towards their illness. They were able to work with positive social relationships among colleagues, especially when their colleagues were knowledgeable about the disease. This is evidenced by a 24% of participants in a semi-structured interview reported a supportive workplace had a positive impact on their careers (Lewis, Sheng, Rhodes, Jackson, & Schover, 2012) and their overall HRQOL.

Discussion: Converging Data

Optimism. Dispositional optimism is conceptualized as a personality trait characterized by the ability to possess positive expectations about the future (Carver & Scheier, 2002) which is perceived as a psychological resource which revolves around health benefits (Rasmussen, Scheier, & Greenhouse, 2009). The result from the current study described an increase of HRQOL in association with the presence of optimism among young cancer survivors, which is in line with most past literatures (Chambers, Meng, Youl, Aitken, Dunn, & Baade, 2014; Hodges & Winstanley, 2012). In the longitudinal quantitative study done by Chambers and colleagues (2014) among 763 colorectal cancer survivors, it was reported that a poor QOL was observed 5 years after the diagnosis of cancer, and one of the risk factors were low levels of optimism. While optimism is able to promote psychological well-being among cancer patients during their treatments (Matthews & Cook, 2009), low level of optimism was found to associate with the development of anxiety and depression, significantly predicting diminished HROOL among cancer survivors (Zenger, Brix, Borowski, Stolzenburg, & Hinz, 2010). Whereas in qualitative study, long-term survivors reported about finding a sense of meaning within their illness, leading to the acknowledgement of their life purposes (Parry, 2003). Such acknowledgement was found to associate with great level of optimism, similarly reported in this current study.

Hopefulness. According to Snyder (2002b), being hopeful involved having a specific goal in life which initiates mental and physical actions, the cognitive thoughts of achieving

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS the goal, and to possess motivation to achieve the goal. Snyder (2002b) also described hope as a factor in promoting good health as well as preventing and treating illness, such as cancer. Study had shown that greater level of hope is associated with better adjustments in coping with cancer (Stanton et al., 2000) and greater tolerance against the pain from treatments (Berg, Snyder, & Hamilton, 2008). Although there were lack of research done on the association between hope and HRQOL among young cancer survivors, the theory of hope enabled the current researchers to understand the positive association between them. Individuals with low hope tend to exhibit more negative mood symptoms, such as anxiety due to the likelihood of negative rumination and worrying (Snyder, 1999a); the most significant concerns and worries among cancer survivors were the fear of recurrence (Lebel, Beattie, Ares, & Bielajew, 2013), which eventually decreases mental HRQOL among these survivors. On the other hand, cancer survivors who exhibit higher hope were more likely to adjust themselves towards their survivorship in which they engage in positive cancer-related thoughts instead of avoiding them (Yuen, Ho, & Chan, 2014). Moreover, higher level of hope was found to relate with lower rate of unhealthy behaviours, such as binge drinking and smoking (Berg et al., 2012); instead, it was found associated with frequent exercising and better nutrition (Coleman, Berg, & Thompson, 2014). Such behaviours were critical factors in reducing the risk of cancer recurrence while increasing HRQOL (Larcombe, Mott, Hunt, 2002). This was found in line with the lifestyle as described by young cancer survivors during the interview. They shifted their dietary pattern to diets containing more vegetables and fish, whereby reducing eating out as well as consuming processed food, as described by 2 survivors.

In conclusion, the current research found that, although not statistically significant, time since recovery was positively correlated with HRQOL as perceived by young cancer survivors. Furthermore, survivors with a Bachelor's degree and Master's degree were found

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS adjusting to survivorship better than those without them or those with a Doctorate degree, as evidenced by the statistical difference between groups. While past literatures found that women often have lower HRQOL as compared to their male counterparts, this current research were not able to support that due to the statistical insignificance in the result, suggesting more research in this matter. Meaningful insights were also gained through qualitative interviews with 5 young adults cancer survivors with various cancer diagnosis. The insights led to the researchers in concluding that optimism and hopefulness were factors in influencing the HRQOL of young cancer survivors, mostly in a positive direction.

Implications of Current Research

The major strength of this current study is the comprehensiveness of the research design, whereby the integration of both quantitative and qualitative components provides a broader understanding of the experience of young adult cancer survivors during their survivorship. These findings are an essential precursor for the development of future services for young cancer survivors. For example, the development of the adjustment to the fear, threat or expectation of recurrence (AFTER) intervention for young adult cancer survivors. Knowing that cancer survivors with excessive fears of recurrence often engage in excessive personal checking (Lasry & Margolese, 1992), the AFTER intervention enables healthcare providers to control such urges through structured therapeutic sessions and expression of fears (Humphris et al., 2008). However, there are no currently known intervention developed in accordance to the needs of young cancer survivors.

The objectives of this current researcher had given rise to new perspectives. Firstly, it was known that higher educational level was associated with greater mental HRQOL.

Therefore, intervention based on psychoeducation can be further explored and implement on young cancer survivors as a route to promote better adjustments to treatment late-effects during survivorship. Moreover, it was found that doctoral post-graduates were notably

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS exhibiting poorer HRQOL which was not reported in detailed previously in past literatures as most literatures categorized all levels of tertiary education as one, instead of separate components. This enable more research to be done in the future to fully explain this pattern. Thirdly, qualitative interviews revealed that optimism and hopefulness were associated with an improved HRQOL among young cancer survivors; however, the lack of past literatures resulted in low empirical support of this result to the existing theory of optimism and hopefulness on HRQOL. This study has been the baseline for future research done within the Malaysian context to associate hope with HRQOL perceived by young adult cancer survivors.

A better understanding of perceived HRQOL among young adult cancer survivors promotes the awareness on the disease, enhance the development of policies in cancer survivorship cares, as well as facilitate the emergence of interventions for cancer support (Yip et al., 2012). While some cancers are preventable, raising awareness on cancer encourages people to screen for detectable cancer and receive early curative, less invasive treatments (Myers et al., 2015). This led to cost savings and a reduction in mortality, at the same time improving HRQOL among cancer survivors.

Limitations and Recommendations for Future Research

The current study has a number of limitations. Firstly, the small sample size created difficulties in generalizing the data to the general population. In order for a general comparison of HRQOL score between the sample and population to be done, a larger sample group should be obtained. However, the current researchers were unable to calculate an appropriate effect size for sample estimation due to the lack of reference scores available in the Malaysian context. Moreover, the participation in the study was voluntarily, especially respondents participating in the qualitative interview. Survivors who were corporative enough to participate in research interviews were mostly more open-minded and with a

HEALTH-RELATED QUALITY OF LIFE AMONG YOUNG CANCER SURVIVORS higher level of optimism and hopefulness. Another sample-related limitation in this study is

higher level of optimism and hopefulness. Another sample-related limitation in this study is the absence of male respondents participating in the qualitative interview. Hence, this may result in response bias where proportion of young cancer survivors were not representation of population incidences; cancer survivors with lower optimism and hopefulness were not represented and exploration was unable to be done on these individuals.

Also, the study was conducted in the capital of Malaysia, Kuala Lumpur. Respondents were to experience greater treatments and services as compared to survivors in the rural areas of Malaysia. Therefore, the life satisfaction may be slightly higher, predicting a greater level of HRQOL as well. For a more diverse data to be obtained, researchers were encouraged to collect data from multiple locations of Malaysia where living lifestyle seemed to differ from one another.

Conclusion

While most research focused on older cancer patients, this mixed method study provides a comprehensive understanding of HRQOL among young adult cancer survivors. The survey results described that time since recovered does has a positive correlation with HRQOL, although there was no statistical significance. Further exploration on demographics also showed a significant difference between levels of education with HRQOL, indicating young cancer survivors with Bachelor's degree and Master's degree having greater HRQOL, and both male and female reporting similar HRQOL scores. The qualitative findings mainly confirmed and extended the understanding of the quantitative results. The integration of both approaches give rise to the idea that HRQOL is influenced due to perceived optimism and hopefulness as described by young cancer survivors. The results from the current research contributed to the research pool in the Malaysian context, providing with new perspectives for further exploration in future researches. With in-depth understanding of HRQOL

perception, interventions for improvement of post-treatment adjustment to life can be developed tailored for young cancer survivors.

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