THE EFFECTS OF GUIDED IMAGERY AND RELAXATION TECHNIQUE ON PSYCHOLOGICAL FUNCTIONING OF CHILDREN WITH CANCER: A RANDOMIZED CONTROLLED TRIAL

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by

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LIST OF ABBREVIATION

RCT Randomized Controlled Trial

GIR Guided Imagery Relaxation

HUSM Hospital Universiti Sains Malaysia

CONSORT Consolidated Standards of Reporting Trials

BMA Bone Marrow Aspirations

PEDSQL Pediatric Quality of Life Inventory

PEDSQL VAS Present Functioning Visual Analogue Scale

WHO World Health Organisation

HRQOL Health-Related Quality of Life

PTSD Post-Traumatic Stress Disorder

PTSS Post -Traumatic Stress Syndrome

ANZCTR Australian New Zealand Clinical Trials Registry

KESAN IMAGERI BERPANDU DAN TEKNIK RELAKSASI DALAM MENINGKATKAN SKOR KUALITI HIDUP DAN PSIKOLOGI KANAKKANAK YANG MENGIDAP KANSER: KAJIAN PERUBAHAN SECARA RAWAK

ABSTRAK

Teknik relaksasi adalah salat satu teknik yang membantu kanak-kanak dalam menangani tekanan. Teknik ini menggalakkan kesihatan jangka panjang dan menenangkan minda. Teknik imageri berpandu dan relaksasi dibangunkan dan telah dijalankan untuk membantu kanak-kanak yang mengidap kanser di Malaysia. Kajian ini bertujuan mengukur keberkesanan Teknik relaksasi dalam mengurangkan emosi negatif pesakit dan meningkatkan fungsi psikologi ketika mereka menerima rawatan kanser. Secara khususnya, kajian ini mengukur perbezaan skor kualiti hidup (PedsQL) dan tahap emosi pesakit (VAS) yang dilaporkan oleh ibu bapa dan pesakit itu sendiri sebelum dan selepas menerima Teknik relaksasi. Enam puluh (N=60) pesakit kanser mengambil bahagian dalam kajian ini. Kanak-kanak yang didiagnosis mengidap kanser dan memenuhi kriteria telah direkrut dari wad onkologi 6 Utara, (HUSM). Soal selidik *PedsQL* dan *VAS* telah di isi oleh pesakit dan ibu bapa sebelum intervensi GIR dijalankan. Pesakit diberi alat MP3 secara individu dan pesakit diberi pendedahan mengenai cara penggunaan alat untuk mendengar skrip relaksasi. Kumpulan intervensi diminta untuk mendengar audio sebanyak 3 kali seminggu dalam masa 3 minggu. Pada akhir minggu ketiga,pesakit dan ibu bapa diminta untuk mengisi PedsQL dan VAS. Mixed (ANOVA) dijalankan unuk mengkaji perbezaan skor *PedsQL* dan *VAS* antara kumpulan intervensi dan kumpulan kawalan sebelum dan selepas intervensi. Terdapat perurunan yang signifikan dalam domain simptom keseluruhan *VAS*, skor kegelisahan, dan skor kesedihan mengikut laporan ibu bapa pesakit dari pra intervensi (Min=31.3, (SP=21.9); Min=26.3, (SP=25.9); and Min=27.3, (SP=22.2) sehingga selepas intervensi (Min=10.5, (SP=7.9); Min=8.57, (SP= 7.55); and Min= 10.0, (SP=8.60) (nilai p < 0.001). Tiada perbezaan yang signifikan dalam skor PedsQL serta skala *VAS* untuk kanak-kanak mengidap kanser (nilai p > 0.05). Walaubagaimanapun, secara keseluruhannya domain PedsQL dalam kumpulan intervensi menunjukkan peningkatan dalam skor. Ini bermaksud ibu bapa melaporkankualiti hidup dan fungsi psikologi anak-anak mereka menunjukkan peningkatan yang lebih baik setelah menerima Teknik relaksasi ini (GIR). Kesimpulannya, Teknik GIR adalah satu alat yang berkesan untuk membantu mengurangkan emosi negatif terutamanya kegelisahan dan kesedihan kanak-kanak mengidap kanser. Alat ini berpotensi membantu pesakit menguruskan tekanan mereka.

Kata kunci: Kanak-kanak kanser, ibu bapa, psikologi intervensi, relaksasi, kesusahan emosi

THE EFFECTS OF GUIDED IMAGERY AND RELAXATION TECHNIQUE ON PSYCHOLOGICAL FUNCTIONING OF CHILDREN WITH CANCER: A RANDOMIZED CONTROLLED TRIAL

ABSTRACT

Relaxation technique is one of helpful tools for children coping with stress. It promotes long-term health by slowing down the body and quieting the mind. Guided Imagery Relaxation (GIR) technique has been developed and piloted to help children with cancer in Malaysia. This study measures the effectiveness of GIR technique in reducing children's negative emotions and in improving their psychological functioning when they are receiving treatment for cancer. In particular, the study measures differences in scores of The Paediatric Quality of Life Inventory 4.0 (PedsQL) and PedsQL(VAS) scale as reported by parent and children before and after their children receiving GIR. Sixty (N=60) children with cancer participated in this study. Children who are diagnosed with cancer and fulfilled the inclusion criteria were recruited from paediatric oncology ward 6 Utara, (HUSM). Using parent-proxy and children report, the VAS and PedsQL were administered before the intervention of GIR. The children were given an individual MP3 player and they were guided on how to use the player and listen to the scripts, so that they will experience relaxation. The intervention involved of hearing the audio for three times a week, in three subsequent weeks (i.e. 3 times a week for 3 weeks). At the end of third week, post-intervention assessments were administered. Mixed ANOVA design were conducted to examine the differences in scores of VAS and PedsQL between intervention and control group before and after the intervention as reported by parents and children. There are significant decrease in domains of children's Total symptom score, Anxiety, and Sadness, in VAS parent-reported from pre-intervention (M=31.3, (SD=21.9); M=26.3, (SD=25.9); and M=27.3, (SD=22.2) to post-intervention (M=10.5, (SD=7.9); M=8.57, (SD= 7.55); and M= 10.0, (SD=8.60) (p < 0.001). There is no statistical significant difference in scores of PedsQ as well as child-reported VAS scale (p > 0.05) However, in all domains of PedsQL in intervention group, the scores increased which means parents reported better quality of life and psychological functioning in their children after receiving GIR intervention. In conclusion, GIR technique is an effective tool that helps to reduce negative emotions especially anxiety and sadness in children with cancer. This GIR tool has potential in helping children to manage their stress.

Keywords: childhood cancer, distress, emotional, intervention, parents, psychological, relaxation.

CHAPTER 1

INTRODUCTION

This chapter introduces several relevant areas needed in this research to build a foundation about the effectiveness of guided imagery and relaxation especially on psychological functioning among children with cancer. This chapter describes the background of the study, statement of problem, justification and benefit of the study. It states both general and specific objectives, as well as hypotheses formulated in regard to this study. Finally, definition of cancer childhood, prevalence, survival rates, mortality rates and theories of guided imagery and relaxation of this research will be elaborated at the end of this chapter.

1.1 Background of the study

Amongst the main health problem in Malaysia is cancer (Lim, 2002). Malaysia Cancer Registry Report showed that around 37 in every 100,000 Malaysia children especially aged 0 to 15 years are at risk of developing cancer with a little higher incidence in boys compared to girls (Lim, Yahaya, & Lim, 2003). As a consequence of the technical advances in treatment and the centralisation of services in specialist centres, a much greater number of childhood cancer sufferers are surviving to adulthood (Walker, 2011). Children are treated with the combinations of radiotherapy, chemotherapy, and surgery depending on a specific cancer (Eiser, Eiser, & Stride, 2005).

The aim of this study is to measure the practice of guided imagery and relaxation as an effective method in improving psychological functioning among cancer children. This technique is presently perceived to be the main alternative therapeutic technique for medical illness, including cancer. This technique has been used in therapy for over some time (Utay & Miller, 2006). However, the paediatric population in general and cancer patients are not exposed to psychologically directed treatment, thus make them unaware of the potential benefits of guided imagery and relaxation techniques. Technique of guided imagery has been increasingly used by healthcare providers in health field with impressive results and outcomes (Utay & Miller, 2006).

1.2 Statement of problem

The problem of cancer in Malaysia is growing and it has become one of the major health problems in Malaysia. It is now the fourth leading cause of death among medically certified deaths. However, majority of patients are diagnosed at a late stage of the disease. National Health and Morbidity Survey indicate a significant proportion of children suffering from cancer, asthma, and other physical disability also show psychological problems (Lim, 2001).

In particular, individual diagnosed with cancer are prone to various degrees of stress and emotional suffering (Mehranfar et al., 2013). From the very beginning of its diagnosis, cancer highly affects the physical, social, psychological, and spiritual dimensions of cancer patient, especially those who are younger, and in a challenging situation (Reisi-Dehkordi et al., 2014). It is well recognised that the diagnosis of cancer and extensive

treatment are extremely stressful life events and could be emotional burdens for children with cancer (Gregurek et al., 2010).

Therefore, measuring the quality of life in children with cancer provides valuable information regarding our young patients to families and health care providers (Varni et al., 2005). This enable us to identify problems which arise from the impact of the disease and its associated treatment as an effort to improve patient's health as a whole.

In the last 20 years, the use of increasingly aggressive method of cancer treatment have become more common. This makes the need for new technique to manage pain, nausea, and other aversive side effects of such therapy has become apparent. Although a variety of behavioural methods have been shown to reduce acute treatment-related pain, there is increasing evidence that these methods are not equally effective. Hypnotic-like method, involving relaxation, suggestion, and distracting imagery, hold the greatest promise for pain management (Redd et al., 2001).

The application of psychological interventions to the treatment and prevention of disease began in the early 1970s. Unfortunately, research is scant on the use of this intervention to control prolonged pain associated with invasive medical procedures. Part of the psychological interventions that are compatible with cancer patients are the cognitive behavioural therapy which can further be divided into interventions that included a range of treatment components including relaxation, guided imagery, cognitive restructuring, biofeedback, and skills training (Hodges et al., 2011). Study from Weydert et al., (2006), evaluated guided imagery as a treatment for recurrent abdominal pain in children and the result showed that the children who receive guided imagery technique had significantly

greater decrease in pain (Weydert et al., 2006), Guided imagery has been used increasingly by healthcare providers in the medical field with impressive results. It is clear that the application of behavioural theory and methods has an important place in the care of patients undergoing invasive cancer treatment. With this, we are also able to provide ongoing healthcare needs which are related to their chronic illness.

1.3 Justification and benefits of the study

This study provides fundamental information about the effectiveness of guided imagery and relaxation (GIR) techniques in improving psychological and quality of life in children with cancer. Guided imagery may help boost the mood and improve the quality of life among children with cancer as earlier researches indicated that guided imagery may offer some benefits to cancer patients especially in terms of emotional health.

1.4 Objectives

1.4.1 General Objective

This study aims to measure the effectiveness of Guided Imagery and Relaxation (GIR) techniques in improving psychological functioning among children with cancer.

1.4.2 Specific Objectives

 To examine the differences of PedsQL Present Functioning Visual Analogue (VAS) - Total symptom scores between intervention and control groups of children at pre and post-assessment levels.

- 2. To examine the differences of PedsQL Present Functioning Visual Analogue (VAS) - Anxiety scores between intervention and control groups of children reported by parent at pre and post-assessment levels.
- To examine the differences of VAS Sadness scores between intervention and control groups of children at pre and post-assessment levels.
- **4.** To examine the differences of VAS Anger scores between intervention and control groups of children at pre and post-assessment levels.
- 5. To examine the differences of PedsQL Present Functioning Visual Analogue (VAS) - Worry scores between intervention and control groups of children reported by parent at pre and post-assessment levels.
- **6.** To examine the differences of VAS Tiredness scores between intervention and control groups of children at pre and post-assessmentlevels.
- **7.** To examine the differences of VAS Pain scores between intervention and control groups of children at pre and post-assessment level.
- **8.** To examine the differences of PedsQL (Quality of Life) Generic 4.0 scores between intervention and control groups of children reported by parents at pre and post-assessment levels.

1.5 Hypotheses

 There will be a significant difference of PedsQL Present Functioning Visual Analogue (VAS) - Total symptom scores between intervention and control groups of children at pre-and post-assessment levels.

- 2. There will be a significant difference of PedsQL Present Functioning Visual Analogue (VAS) Anxiety scores between intervention and control groups of children reported by parents at pre-and post-assessment levels.
- **3.** There will be a significant difference of VAS Sadness scores between intervention and control groups of children at pre- and post-assessment levels.
- **4.** There will be a significant difference of VAS Anger scores between intervenon and control groups of children at pre- and post-assessment levels.
- **5.** There will be a significant difference of VAS Worry scores between intervention and control groups of children at pre- and post-assessment levels.
- **6.** There will be a significant difference of VAS Tiredness scores between intervention and control groups of children at pre- and post-assessment levels.
- **7.** There will be a significant difference of VAS Pain scores between intervention and control groups of children at pre- and post-assessment levels.
- **8.** There will be a significant difference of PedsQL (Quality of Life) Generic 4.0 scores between intervention and control groups of children reported by parents at pre-and post-assessment levels.

1.6 Childhood Cancer

1.6.1 Definition of Cancer

The Convention on the Right of the Child (UNCRC) defines children as "every human being below the age of eighteen years (Skelton, 2007). Cancer is not only illness, it consists of a variation of malignancies in which irregular cells are divided into an uninhibited way. These cancer cells can attack nearby tissues and can move via blood to other parts of the body (National Cancer Institute, 2015).

The common types of cancer among patient aged 0 to 14 years especially in the United States are leukaemia, and followed by brain, and other central nervous systems such as tumors, lymphomas, and soft tissue sarcoma of which partial of it are, rhabdomyosarcoma, neuroblastoma, and kidney tumors (Siegel et al., 2017).

Solid tumor is an abnormal mass of tissue that usually does not contain cysts or liquid areas. Solid tumor may be benign, or malignant. Different types of solid tumors are named for the type of cells that form them. Example of solid tumors are sarcomas, carcinomas, and lymphomas. (National Cancer Institute, 2018).

Lymphoma is a cancer of the lymphatic. It affects a type of white blood cells known as lymphocytes that help fight disease in the body and play an important role in the immune system. There are two basic categories of lymphomas. One kind is Hodgkin lymphoma, which is marked by the presence of a type of cell called the Reed-Sternberg cell. The other category is non-Hodgkin lymphomas, which include a large, diverse group of cancers of immune system cells (American Cancer Society, 2012).

Leukaemia is a cancer of the blood or bone marrow. Bone marrow produces blood cells. Leukaemia can happen when there is a problem with the production of blood cells. It usually affects the leukocytes, or white bloods cells (National Cancer Institute, 2018).

In Malaysia, the most common childhood cancer types in the population are leukaemia, lymphomas, neuroblastoma, retinoblastoma (Lim, 2002).

1.6.2 Prevalence

This section covers prevalence childhood cancer happened worldwide, specifically in the United States and Malaysia.

Although cancer in children is rare, it is the leading reason of death among children in the United States. In 2017, it was predicted that 15,270 children and adolescents aged between 0 to 19 years would be diagnosed having cancer and 1,790 children would be deceased. Among children aged between 0 to 14 years, it was estimated that 10,270 would be identified with cancer and 1,190 would be deceased in 2017 (Siegel et al., 2017).

Insofar to the above mentioned, it is similar in Malaysia whereby cancer is the leading reason of premature death and is ranked as the fourth, after cardiac and circulatory diseases, infection and injury (Ho et al., 2017).

Malaysian National Cancer Registry (MNCR) showed that around 37 in every 100,000 Malaysian children especially aged 0 to 15 years are at risk of developing cancer. Ariffin et al., (2017), cancer is not altogether uncommon in children as it could be diagnosed at any age.

1.6.3 Survivor Rates

Cancer survivor refers to any individual who has been identified with cancer, be it patients who are presently fighting with this illness, and persons who are healed from cancer (DeSantis et al., 2014). Effective treatments for many types of childhood cancer have been developed, and improvements in survival have been reported (Jones, 1987). Improvements in survival are likely related to the advances in treatment and declined in surgical mortality, and cancer survival rates for all cancer patients have been improved since 1975 (National Cancer Institute, 2017). Children with cancer survival rates have increased over the past 30 years. Now, more than 75% of patient are expected to survive their illness (Greenlee, Hill-Harmon, Murray, & Thun, 2001).

The survivor rates were 7 to 9% lower in Europe compared to the one in the United States, especially among patients with neuroblastoma and Wilms Tumor, while 8% higher cancer patients with retinoblastoma (Gatta, Capocaccia, Coleman, Ries, & Berrino, 2002). Therefore, the treatment rate of childhood cancer has improved from almost 25% in the 1960s to more than 75% in recent years (Griffiths, Schweitzer, & Yates, 2011).

More than 20,000 young Australians have survived childhood cancer, but only 4 out of 5 experiences at least one physical or mental health issue so-called "late effects" of treatment. Physical effects include heart disease, osteoporosis, and obesity. Psychological effects such as anxiety and depression are reported to be occurred in 50% of survivors (Cancer Council NSW, 2016).

In short, sixty years ago, cancer is always being regarded as a death sentence for children. Today, 8 out of 10 children survived. However, these improvements are not even across cancer type. Survival rates have sat at about 50% in a decade (Australian Institute of Health and Welfare, 2012).

1.6.4 Mortality Rates

Mortality rates are the number of deaths of which cancer is the underlying reason (Wolfe et al., 2000). Cancer remains of the leading reason of death among children in the United States, and its significant short-term and long-term treatments toxicities continue to give impacts to majority of the children having cancer (Raetz et al., 2015).

One-fourth of childhood cancer arises in the central nervous system and accounts for the major quantity of cancer death in childhood. Not only that, a significant morbidity of 60% of the survivors are left with disability (Kaleyias, Manley, & Kothare, 2012)

The types of the cancer with the highest mortality rates vary in age, although brain cancer and leukaemia are the leading causes of cancer-related death in children across all ages. Liver cancer is the fourth most common cause of cancer-related mortality in children ages 3 and younger (Group, 2010). In addition, neuroblastomas is known to be the comparatively common cause of cancer-related mortality in younger children, while bone and joint cancers, and non-Hodgkin lymphomas are the common reasons of cancer-related mortality in older children (DeSantis et al., 2014).

One thousand five hundred children in worldwide deceased from cancer (Global Cancer Facts and Figures, 2012). Cancer is ranked to be the fourth in the list of diseases that cause death among Malaysians at government hospitals (Farooqui et al., 2013).

Insofar to the above mentioned, improved implementations of guidelines treatment that include psychological intervention are likely to affect morbidity and mortality Duncan, Weir, Strachan, & Tulloch-Reid (2014), in childhood cancer. Guided imagery and relaxation technique are examples of recommended psychological treatment serves this purpose.

1.7 Theories of Guided Imagery and Relaxation

1.7.1 Psychoneurological Theory

Guided imagery is based on psychoneurological theory developed by Green and Green in Vines (1988), who suggest when a person creates and holds an image in their mind, cerebral cortex and limbic system are activated. Subsequently the hypothalamus is activated to create a positive change in the autonomic nervous system. The imagination is hypothesised to induce relaxation, emotional comfort and physiological reactions as well as indirectly influencing children's cognition towards positive and calming thoughts (Vines, 1988). This theory connects the role of imagery to healing.

1.7.2 Bio-Informational Theory (Emotional Imagery)

Lang's Bio-informational theory of emotional imagery has gained popularity in the scientific community as a possible explanation of guided imagery's physiological effects in the body. Lang assumes that image in brain is limited structure. This structure includes a motor program and serves as a prototype for overt behavioral expression. Lang maintains that mental imagery is not simply a picture in the brain, but is integrated thoroughly with an individual's physiological response patterns (Lang, 1979).

Based on these two theories, we assume that guided imagery would have a positive relaxation impact on the listener, thus improve their overall psychological functioning.

CHAPTER 2

LITERATURE REVIEW

This chapter reviews literature pertinent to the current study which includes the psychological effects of cancer on children, psychological intervention conducted on children with cancer, and the effects of psychological intervention on children with cancer. In particular, the use of guided imagery and relaxation (GIR) interventions in health setting is reviewed in this chapter.

2.1 Psychological Effects of Cancer on Children

The psychological effects of cancer on children include negative emotions that oftenly expressed by children which are anxiety, pain, worry, fatigue, stress, and anger. In addition, cancer would affect children's overall quality of life (QoL).

2.1.1 Anxiety

Anxiety is one of the most common psychological effects exhibited by children with cancer. Anxiety can be defined as an inner uneasy emotion, which may be aroused by a threat to well-being (Davies, Blakeley, & Kidd, 2001). Freud defined anxiety as something perceived an emotional state that includes the feeling of apprehension, uneasiness, pressure, nervousness, fear, (Spielberger, 2010) and restlessness, (Rees, 1995) and are accompanied by physiological stimulation (Spielberger, 2010). In particular, the

physiological effects involved muscular tension, sweating, respiratory disturbances, heart palpitations, nausea, and dizziness (Rees, 1995).

The prevalence of pre-operative anxiety is high and is described to range from 40% to 60% amongst young children (Kain, Mayes, O'connor, & Cicchetti, 1996). Not only that, previous reports estimated that 60% of children experienced anxiety immediately prior to surgery (Wollin, Plummer, Owen, Hawkins, & Matarazzo, 2003). Anxiety is found to be the highly prevalent effect among cancer patients (Stark & House, 2000), indicating that the stress experienced by the patients can lead to the development of anxiety symptoms. Data report from the Childhood Cancer Survivor Study indicated that 13% of fighters anxiety were related with their cancer experience (Kendall, Aschenbrand, & Hudson, 2003). In Malaysia, a study of anxiety among Malaysians' breast cancer patients found that the rate of anxiety was 31.7 % (Ng et al., 2015). Hassan et al. (2015) claimed that young aged and financial burden were some of the factors that could be associated with anxiety among the Malaysians' cancer patients (Hassan et al., 2015).

Generally, anxiety is known to potentiate the experience of pain. Anxiety commonly accompanies acute pain and the role of anxiety is considered paramount in the treatment of pain (Woo, 2010). A high level of anxiety can be associated with negative postoperative consequences including nightmares, food rejection, enuresis, and negativity (Wollin et al., 2003).

Spielberger (2010) divided anxiety into two categories, which are first, state-anxiety, and second, trait-anxiety. State-anxiety is considered as a passing condition of an individual from moment to moment. Trait-anxiety is a constant tendency of individual to perceive

any negative situation as a threat. Spielberger (2010) developed a scale to measure anxiety called the State-Trait Anxiety Inventory (STAI) which contains two subscales. Firstly, the state-anxiety assesses temporary anxiety symptoms, for example "I feel upset". Secondly, trait-anxiety measures chronic or trait-anxiety symptoms, for example "I have disturbing thoughts". The trait-anxiety scale is consists of 20 statements that asked the respondents to describe how they generally feel (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). While, the state-anxiety scale is consists of 20 statements to indicate how the respondents feel at a particular moment in time (Spielberger et al., 1983).

2.1.2 Pain

Pain is the most common cancer effect and cancer treatment can cause pain as well (Enskär et al., 2007). Pain is defined as an unpleasant sensory and emotional involvement that are to be described in terms of such damage (Moisset & Bouhassira, 2015; Sherbourne, 1992). Pain is a complex (McCarthy et al., 2010), multi-dimensional, and subjective experience that consists of psychological, sensory, emotional, cognitive, and behavioural components (Broome, Rehwaldt, & Fogg, 1998).

Also, pain can be considered as a significant burden because it is of the most feared symptoms to cancer patients. In a systematic review of 28 epidemiologic surveys of cancer pain, 14 to 100% of patients reported pain symptoms (Goudas, Bloch, Gialeli-Goudas, Lau, & Carr, 2005). Mercadante (2004) claimed that about 50% of children experienced cancer-related pain at diagnosis level or during the active treatment phase.

However, previous researches have focused more on procedural pain intervention, the practice of hospital pain teams and specialists, pain assessment, pharmacologic

improvements on analgesia, and complementary and other medicine therapies (Hockenberry, 2004). Other researches reported that treatment interventions must focus on treating the physical and emotional effects of pain (Varni, Burwinkle, & Katz, 2004).

A large variation of pediatric pain scoring tools have been developed via different methods and designs for children with different cognitive abilities (Cohen et al., 2007). Self-assessment tools are commonly used (Stewart et al., 2004). However, children's pain evaluation is complex as different results may occur based on to the children's age, mental development, type of pain, and presenting condition (Somers, Beckett, Sedgwick, & Hulbert, 2001).

Savino et al., (2013) proposed that the struggles in measuring pain among patients is known to be the potential inconsistency between their awareness and involvement of pain and their expression. Self-report especially Faces scales are commonly used to assess pain intensity among children in spite of apprehensions regarding understanding ability (Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006). In Savino et al. (2013) study, they revealed that scales have five to seven faces, which are intended to provoke an indication of pain intensity. Other than that, the study gives detail information rather than a simple binary "pain" or "no pain" responses (Savino et al., 2013).

Hockenberry and Hooke (2007) stated that 40% of all pain episodes were process related, i.e., cancer survivors continue to relieve the intense memories of the painful procedures that they have underwent during treatment. The physical, mental, and emotional consequences of pain have manifested itself throughout the kid's level of functioning, coping and behaviour (Schwimmer, Burwinkle, & Varni, 2003).

Children with cancer typically undergo many painful medical procedures, leaving patients and survivors vulnerable to procedures-relating anxiety. In a study of pain management among children aged 3-18 undergoing medical procedures (Weisman, Bernstein, & Schechter, 1998), children below 8 years old who had received the first trial placebo, sustained to feel higher level of discomfort during subsequent procedures which is performed together with pain management. Hedström et al., (2003) stated that painful medical procedures and anxiety of pain were amongst the important components which contribute towards suffering of symptoms among children aged 0-19 years old.

Pain can be assessed via self-report, behavioural reflection, or physiologic procedures, depending on the age of children and communication abilities (Correia and Linhares, 2008). The most commonly used is The Wong Baker-FACES scale developed by Wong and Baker in 1988. The faces scales (FACES) has been established in multiple pediatric settings for pain assessment. FACES is based on the combination of face pictures and numbers and particularly useful for young children who may not have the vocabulary knowledge to explain their pain level (Mc Cann, Wang, Zheng, & Eccleston, 2012).

2.1.3 Worry

Worry is a common psychological issue which sometimes, experienced by most individuals in their lives (Davey, Hampton, Farrell, & Davidson, 1992). Worry is a main reasoning characteristic of anxiety, and has been labelled as a chain of opinions and images, negatively effect and comparatively uncontrol (Hirsch & Mathews, 2012). Worry is frequently experienced as a state of anxiety, fear, concern, or restlessness about one's

present and future involvements. It is a practical response to a continuing and real risk in life (Yi, Kim, & Sang, 2016).

Similarly, worry is very common among children. Community studies have found out that up to 80% of the primary school children aged 8-12 years are worry, generally about their well-being, dying, disease, school, and community issues (Muris, Meesters, & Gobel, 2001). According to Muris, Merckelbach, Gadet, & Moulaert (2000) children aged between 7 to 9 are most likely to worry about personal harm or harm to others and health. Then, children aged between 10 to 12 are worry about their behavioural competence and social evaluations. Other than that, according to Muris et al., (1998), worry is very common among adolescents and children. In their study among children aged 8 to 13 years, they found that 68.9% of participants reported to worry at least "now and then". Girls have also been found to worry more than boys, especially regarding academic performances, sports, and social competences (Muris et al., 2000).

Worry is a reasonable ongoing reaction and a real threat for persons with chronic illness (Herschbach et al., 2005) such as cancer. Individuals with a physical disease, including cancer patient, typically fear about its development or reappearance. Worry is frequently linked to doubt, which is a essential feature in enduring childhood cancer survivor (Parry, 2003). Yi, Kim and Sang, (2016) suggested that uncertainty can greatly influence the emotions of children with cancer, which can up and down between desire and fear. Cancer survivors express a wide variety of worries. They may fear about the slow medical effects of their treatment, rehabilitation into their social situation, or their future families (Yi, Kim & Sang 2016). Survivors probably experience more worry, concern about recurrence and anxiety at particular times during the cancer process, especially after eight diagnoses,

when treatment begins and when treatment ends (Mullens, McCaul, Erickson, & Sandgren, 2004).

Childhood worry measuring scale includes The Penn State Worry Questionnaire (PSWQ) for children, The PSWQ is the most widely used instrument to assess general characteristics of worry among children and adolescents from age 7 to 17 (Chorpita et al., 1997). Other than that, PROMIS Emotional Distress-Calibrated Anger Measure-Pediatric is another instrument that assesses the pure domain of worry in children from the age of 11 to 17 (Irwin et al., 2012).

2.1.4 Tiredness

Tiredness can be defined as the observation of an uncommon feeling of entire body which is different from the normal sense of fatigue, experienced by normal person (Blaauwbroek et al., 2009). Children with cancer defined fatigue as a profound sense of being bodily tired or having trouble with body movement such as opening their eyes or using their legs or hands (Yi, Kim & Sang 2016).

The prevalence of tiredness has been stated in 80% to 99% between cancer patients who experience treatment with chemotherapy or radiotherapy (Hofman et al., 2007). Tiredness is the most commonly anticipated adverse effects of cancer treatment whereby 95% patient arranged to receive chemotherapy or radiotherapy are expected to experience some level of fatigue throughout their treatment (Hofman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007).

Fatigue is one of the most common and debilitating symptoms experienced by patient with cancer (Hofman et al., 2007). Children with cancer face several symptoms, especially in

the procedure of their treatment (Arslan, Basbakkal, & Kantar, 2013). This means fatigue can cause many others symptoms such as sleep disorder, temper, sadness, pain, nausea, and decrease in physical routine (Yılmaz, 2012).

It is established that similarly to adult, children who are in the process of undergoing treatment for cancer experience disease-related fatigue as multi-dimensional symptoms, resulting in profound tiredness and unusual need for rest (Bennett, Goldstein, Friedlander, Hickie, & Lloyd, 2007). Here, the multi-dimensional aspects involve the physiological factors and psychological factors (Ryan et al., 2007). Hockenberry-Eaton et al., (1998) examined the observations of fatigue in children with cancer and found the children who experience physical symptom would feel tired to move and run. While, psychological fatigue is expressed through their reduced capacity for attention, and knowledge, as well as trouble in short-term memory and feeling anger and sadness (Ryan et al., 2007).

Different phases of disease and different types of treatment would also affect fatigue experienced by children with cancer. After their chemotherapy treatment, a symptom such as the feeling of tiredness is oftenly reported among children (Hofman et al., 2007). Chemotherapy alone or with combination seems to cause more severe fatigue then radiation alone (Scher et al., 1998). Treatment related-fatigue may persist and extended after the end of the treatment (Andrykowski, Curran, & Lightner, 1998).

The effects of fatigue on children with cancer can be devastating and this include immunosuppression, lack of appetite, muscle wasting, and slowed physical healing (Punyko et al., 2007). Children with cancer are commonly reported to have lack of energy during the progression of their treatment (Portenoy et al., 1994). In addition, children with

brain tumors seem to experience more fatigue than those with leukaemia (Meeske, Katz, Palmer, Burwinkle, & Varni, 2004).

A wide variety of instruments were used to measure fatigue which include Piper Fatigue Scale (PFS) developed by Piper et al., (1998). It is one of the commonly used instruments to measure behavioral, affective, sensory, and mood attributes of fatigue. The Fatigue Severity Scale developed by Krupp, LaRocca, Muir-Nash, and Steinberg, (1989) primarily focuses on the motor aspect of fatigue by which its main emphasis is to assess the severity of fatigue symptom and impacts on an individual's daily activities. As for this study, The Present Functioning Visual Analogue Scale (VAS) (Sherman, Eisen, Burwinkle, & Varni, 2006) will be used to measure the present functioning among children. The VAS also assesses children's, sadness, anxiety, anger, worry, and pain via parent-report and child own report (Sherman et al., 2006).

2.1.5 Stress

Stress is defined as a process when a individual interprets external and internal factors as burdening on their own resources, value, and goals. Stress occurs if demands are perceived as difficult or beyond the person's abilities or resources to cope (Son et al., 2007).

The diagnosis of cancer presents children and adolescents with significant stress which are associated to the illness, its treatment, disturbances in daily life, and worries about the future (Compas et al., 2014). There are the several stages of the disease that may induce the emotional response in children who are identified with cancer (Othman et al., 2013). The initial phase is being claimed to be the most stressful moment (Katz & Jay, 1984).

Literatures have shown that the diagnosis of cancer in a children represents a highly stressful experience which reverberation throughout the family and has different impacts on each family member with cancer (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999).

Childhood cancer is a stressful and can be regarded as a possibly distressing experience for children and their family. There are some evidences to suggest that the incidence of <u>post-traumatic stress symptoms (PTSS)</u> is higher for children on active treatment than those long-term survivors (Phipps, Long, Hudson, & Rai, 2005). Symptoms of post-traumatic stress are commonly reported among young adult survivors of childhood cancer (Katula, 2007). It is estimated 20.5% of childhood cancer survivors' population met the criteria for lifetime post-traumatic stress disorder (PTSD) (Hobbie et al., 2000).

Cancer diagnosis is a distressing event, and some long-term survivors of childhood cancer meet the PTSD conditions, years after their treatments have ended (Meeska, 2001). PTSD symptoms have been recognized in both children and adult patients with cancer while they are on active treatment and years after their successful achievement therapies. Prevalence estimations for PTSD in patient with cancer and survivors range from 2.5% to 20% (Alter et al., 1996).

The assessment of stress which includes Perceived Stress Scale (PSS) developed by Cohen, Kamarck, and Mermelstein (1983) is commonly used to assess self-report of globally perceived stress. Another assessment used to measure the level of stress is Standard Stress Scale (SSS) (Gross & Seeba, 2016).

2.1.6 Anger

Anger is an internal state that regulated a sort of interaction together with situation (del Barrio et al, 2004). Anger expression in children has been related with a number of negative well-being and psychological outcomes, including higher blood pressure, psycho-somatic symptoms, poor perceived health, depression, violence, and external problem (Kerr & Schneider, 2008). Anger, hostility, and aggression are the central concepts in effort to comprehend the role of psychological issues in the development of many physical health problems (Kern & Friedman, 2011).

Literatures have shown that the evaluation of anger in children is very less developed (del Barrio et al, 2004). The assessment of anger includes the Pediatric Anger Expression Scale (PAES) developed by Jacobs & Blumer (1985). It is a 10 items self-reported measurement to asses children's anger expression The Pediatric Anxiety Scale (PANX) by Jacobs, Phelps, & Rohrs, (1989) measures the anxiety and anger as the emotional states and personality traits. For this study, we will use the Present Functioning Visual Analogue Scale (VAS-Anger) to measure the children's anger at the present moment of functioning.

2.1.7 Quality of life (QoL)

Quality of Life (QoL) can be measured in specific terms, and its assessment has been developed on present lifestyle, previous experience, expectation for the future, vision and ambition (Haviland et al., 2017). Quality of life can be observed from the community and it includes emotional and physical consequences of health care treatments.

Quality of life comprises all parts in life and experiences and it takes the impact of disease and dealing with treatment (Haviland et al., 2017). Cancer affects normal daily routine of children as it touches a variety of aspects of life such as physical activities, relationships

between families and friends, emotional well-being, and difficulties in coping with the symptoms experienced during their illness (Lysaker et al., 2011).

Children with chronic illness such as cancer, asthma, and diabetes have long been thought to have a negative impact in their QoL (Kourkoutas, Georgiadi, & Plexousakis, 2010). QoL among children with cancer is likely to be conceded with the pain of illness, lack energy to enjoy daily activities, and fear about their future (Eiser, 2005). The physical dimensions of QoL among children were always connected to pain and vomiting (Hockenberry, 2004).

Hamidah et al., (2011) used Health-Related Quality of Life (HRQOL) scale for children with acute leukaemia and compared the score between those with chemotherapy maintenance and those who were off-treatment. The findings showed that patient with acute leukaemia on chemotherapy maintenance experienced significantly poorer HRQOL compared to those off-treatment ((Hamidah et al., 2011).

Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Questionnaire was developed by Varni and Limbers, (2009) to measure QoL in children. The PedsQL is a flexible approach in assessing health-related quality of life in both normal children and those with chronic health conditions. The PedsQL consisted of four elements of functioning's including Physical, Emotional, Social and School Functioning (Varni & Limbers, 2009). In PedsQL, items were reversely scored and linearly transformed to a 0-100 scale, so that higher scores indicated better quality of life. The PedsQL 4.0TM Generic Core scale alone was translated into multiple international languages with numerous data in both healthy and chronic children (Varni, Seid, & Kurtin, 2001).