



UNIVERSITI PUTRA MALAYSIA

***THE MEANING OF RESILIENCE AMONG ADOLESCENT CANCER
PATIENTS AND THEIR CAREGIVERS IN MALAYSIA***

ZAINAB CHAUDHRY

FEM 2017 22



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By

ZAINAB CHAUDHRY

**Thesis Submitted to the School of Graduate Studies, Universiti Putra
Malaysia, in Fulfillment of the Requirements for the Degree of
Doctor of Philosophy**

May 2017

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DEDICATION

I would dedicate my work to my 5 years old daughter for her patience, her cooperation and her understanding; my beloved husband for his support, his dedication towards me and my work and his consideration; and my father, for dreaming big about me and motivated me enough to live that dream.....



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UPM

Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfillment of the requirement for the Degree of Doctor of Philosophy

THE MEANING OF RESILIENCE AMONG ADOLESCENT CANCER PATIENTS AND THEIR CAREGIVERS IN MALAYSIA

By

ZAINAB CHAUDHRY

May 2017

Chairman : Associate Professor Mansor Abu Talib, PhD
Faculty : Human Ecology

Cancer is one of the most critical and soaring health related issues in the present times. The severity and adversity of this disease is augmented many times when it affects the young adolescents. Whilst dealing with all the illness related tautness and despondency, there are individuals and families who have managed to shield themselves against all or most of the damaging impacts. This shield emerges at the time of the diagnosis and evolves through the treatment phase till the recovery phase, characterized by the positive attributes like resilience. It reframes the life style and thought patterns from pessimism to optimism.

This study 'The Meaning of resilience amongst adolescent cancer patients in Malaysia and their caregivers' is conducted to explore the way adolescent cancer patients and their caregivers translate the concept of resilience whilst highlighting the factors enhancing it. The study was designed in the Malaysian backdrop as there is a scarcity of local literature on adolescents, who were the main informants of the study. The study is a qualitative one conducted using the interpretive phenomenological analysis (IPA) method. The semi-structured in-depth interviews were conducted with five Muslim adolescent cancer patients and their caregivers (mothers), from Hospital Kuala Lumpur (HKL); therefore, it generated two sets of data. The patients were suffering from different types of cancer, including blood cancer, brain tumors, and bone cancer. They had been going through the active treatment phase for the last 6 to 12 months, at the time of interview. The treatment modalities included radiation, chemotherapy, bone marrow transplants, and surgeries. They all belonged to middle class families of Malaysia, five caregiving mothers, four had left their jobs due to their child's illness. However, one mother was still working to manage the finances for the family. All the adolescents and caregiving mothers could communicate and understand English; however, some

needed to explain and elaborate on the answers in the Malay language. To counter this issue, a translator, fluent in both English and Malay assisted the investigator.

The results identified seven themes for data set 1 and six themes data set 2 based on the analysis of the corpuses. It was concluded from the analysis that the concept of resilience has its unique manifestation in the Malaysian culture where it is strongly influenced by the strong spiritual beliefs, emotions, family relations, and bonding, especially motherhood, along with the positive personal attitude towards life after cancer. These factors not only shaped their definition of resilience but also contributed in enhancing this positive attribute. The themes for both data sets have impact and linkage with each other, which signify the notion that resiliency like any other attribute, is deeply embedded in the families. The definition of resilience for adolescents and their caregivers is a highlight of the study which is *“Resilience is a process characterized by acquiring spiritual conviction, strength of motherhood, appreciation for assets of life and recognizing the unique personal potential which help in rebounding from the adversity of illness.”*

The study has also proposed assumptions for the theoretical models for both adolescents with cancer and their care giving mothers; namely, the model of resiliency for adolescents with cancer (MRAC) and resiliency model of maternal stress and resilience (RMMSR). The study recommends further research in this area to cultivate the understanding of this significantly dynamic and relevant concept, based on this baseline and the preliminary study, in Malaysia. It can facilitate the health care providers and can have a wider impact on the reframing and restructuring life styles of the patients and their families after their cancer diagnosis. To reinforce, polish, and explore the resiliency capacities and positive attributes in adolescents with cancer and their caregivers, an initial outline of a counseling protocol has been proposed in the study highlighting the needs of the young patients and their caregivers, health system and culture of Malaysia.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia
sebagai memenuhi keperluan untuk Ijazah Doktor Falsafah

**PENGERTIAN DAYA KETAHANAN DALAM KALANGAN PESAKIT
BARAH REMAJA DAN PENJAGA MEREKA**

Oleh

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Barah ialah satu daripada isu-isu berkaitan kesihatan yang paling kritikal dan semakin meningkat pada masa ini. Tahap keseriusan dan kesengsaraan yang dialami bertambah berlipat ganda apabila ia melibatkan anak-anak remaja. Dalam menangani ketegangan dan kekecewaan yang berkait dengan penyakit yang dialami, terdapat individu-individu dan keluarga yang berjaya melindungi diri mereka daripada semua atau kebanyakan daripada kesan-kesan buruk yang boleh timbul. Perlindungan ini muncul pada masa pesakit diberi diagnosis dan beransur-ansur berubah semasa melalui fasa rawatan sehingga fasa pemulihan. Sifat melindungi diri ini bercirikan sifat-sifat positif seperti daya ketahanan diri. Ia membentuk semula gaya hidup dan pola pemikiran pesakit daripada sifat pesimis kepada sifat optimis.

Kajian 'Pengertian daya ketahanan dalam kalangan pesakit barah remaja dan penjaga mereka di Malaysia ini telah dijalankan untuk mengkaji cara pesakit-pesakit barah remaja dan penjaga-penjaga mereka menterjemahkan konsep daya ketahanan diri di samping menonjolkan faktor-faktor yang menggalakkannya. Kajian ini direka dengan berlatarkan Malaysia kerana terdapat sangat sedikit bahan penulisan tempatan tentang remaja yang merupakan pemberi maklumat utama kepada kajian ini. Kajian ini ialah kajian kualitatif yang menggunakan kaedah analisis fenomenologi interpretatif (AFI). Temu bual separuh berstruktur yang mendalam telah dijalankan dengan lima orang pesakit barah remaja beragama Islam dan penjaga-penjaga mereka (ibu) di Hospital Kuala Lumpur (HKL); oleh itu, ia telah menghasilkan dua set data. Pesakit-pesakit ini menghidap jenis barah yang berbeza, termasuk barah darah, ketumbuhan otak dan barah tulang. Pada masa temu bual dijalankan, mereka telahpun selesai menjalani fasa rawatan aktif selama 6 hingga 12 bulan. Modus rawatan termasuk radiasi, kemoterapi, pemindahan sumsum tulang dan pembedahan. Kesemua mereka datang daripada keluarga kelas pertengahan dan dijagai oleh lima orang ibu, yang mana empat daripadanya telah berhenti kerja untuk

menjaga anak mereka. Namun begitu, seorang daripadanya masih meneruskan pekerjaan beliau bagi menampung kewangan keluarga. Kesemua remaja dan ibu mereka boleh berkomunikasi dan memahami Bahasa Inggeris; walau bagaimanapun sebahagian daripada mereka terpaksa menggunakan Bahasa Melayu untuk menjelaskan dan menghuraikan jawapan mereka. Bagi mengatasi masalah ini, seorang penterjemah yang fasih dalam kedua-dua Bahasa Inggeris dan Melayu telah membantu penyelidik.

Keputusan yang diperolehi telah mengenal pasti tujuh tema untuk data set 1 dan enam tema untuk data set 2 berdasarkan analisis korpus-korpus tersebut. Satu rumusan telah dibuat daripada analisis tersebut bahawa konsep daya ketahanan diri mempunyai manifestasinya yang unik dalam budaya Malaysia yang mana ia sangat dipengaruhi oleh kepercayaan rohani yang kuat, emosi, hubungan kekeluargaan dan pengikatan, terutamanya ikatan anak-ibu berserta dengan sikap peribadi yang positif terhadap kehidupan selepas barah. Faktor-faktor ini bukan sahaja membentuk definisi daya ketahanan diri bagi mereka tetapi juga menyumbang dalam meningkatkan lagi sifat-sifat positif ini. Tema-tema untuk kedua-dua set data mempunyai impak dan perkaitan antara satu sama lain yang menunjukkan tanggapan bahawa daya ketahanan, seperti mana-mana sifat lain, telahpun tertanam dalam keluarga. Definisi daya ketahanan untuk remaja dan penjaga mereka adalah penekanan yang diberikan dalam kajian ini, iaitu *“Daya ketahanan ialah satu proses yang dicirikan dengan mendapatkan keyakinan rohani, kekuatan sifat keibuan, penghargaan terhadap aset kehidupan dan mengiktiraf potensi peribadi yang unik, yang membantu dalam usaha untuk kembali bangkit daripada kesengsaraan penyakit yang dialami.”*

Kajian ini juga mencadangkan andaian-andaian untuk model-model teori bagi remaja dengan barah dan ibu-ibu yang menjaga mereka; iaitu, model daya ketahanan untuk remaja dengan barah (MRAC) dan model daya ketahanan untuk tekanan dan daya ketahanan ibu (RMMSR). Kajian ini mengesyorkan penyelidikan lanjut dijalankan dalam bidang ini untuk memupuk kefahaman terhadap konsep penting yang dinamik dan relevan ini, berdasarkan garis dasar ini dan kajian permulaan di Malaysia. Ia boleh membantu para penyedia penjagaan kesihatan dan boleh mempunyai impak yang lebih luas terhadap pembentukan dan penstrukturan semula gaya hidup pesakit-pesakit dan keluarga mereka selepas didiagnosis dengan barah. Untuk mengukuh, menggilap dan meneroka keupayaan daya ketahanan dan sifat-sifat positif dalam diri remaja dengan barah dan penjaga-penjaga mereka, satu garis kasar awal bagi protokol kaunseling telah dicadangkan dalam kajian ini dengan menekankan tentang keperluan pesakit-pesakit muda dan penjaga mereka, sistem kesihatan dan budaya Malaysia.

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-----Allhamdullillah-----

I certify that a Thesis Examination Committee has met on 19 May 2017 to conduct the final examination of Zainab Chaudhry on her thesis entitled "The Meaning of Resilience among Adolescent Cancer Patients and their Caregivers in Malaysia" in accordance with the Universities and University Colleges Act 1971 and the Constitution of the Universiti Putra Malaysia [P.U.(A) 106] 15 March 1998. The Committee recommends that the student be awarded the Doctor of Philosophy.

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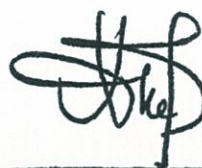
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LIST OF ABBREVIATIONS

ACS	American Cancer Society
ALL	Acute Lymphoblastic Leukemia
APA	American Psychological Association
ARM	Adolescent Resilience Model
CNS	Central Nervous System
CRC	Clinical Research Center
CSFP	Commonwealth Scholarship and Fellowship Plan
HKL	Hospital Kuala Lumpur
IPA	Interpretive Phenomenological Analysis
MOH	Ministry of Health
MOHE	Ministry of Higher Education
MRAC	Model of Resilience for Adolescents with Cancer
NCI	National Cancer Institute
NCR	National Cancer Registry
NGO	Non-Government Organization
NMRR	National Medical Research Registry
RMMSA	Resiliency Model of Maternal Stress and Aaptation
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

Cancer, although said to be due to “unexplainable” genetic mutations, is, however, somehow linked with what we eat and how we live in one way or another. This horrific disease is just as ugly as it sounds, if not more so. It leaves the patient and the ones around the patient all in a state of constant anxiety and psychological distress apart from the physical implications of the disease. It is, therefore, even more important for the psychologists to jump in and provide a smoother and comfortable buffer zone for the patients as well as the apparently healthier family and caregivers who fail to complain yet suffer in silence. These people, to make up for a viable support system for the patient, need to be supported themselves in a manner that paves way for the moral support as well as inculcation of the belief in the prospect of a brighter side of the picture. The significance of this support system and positive attributes becomes even more prominent when it affects the young adolescent cancer patients. This brighter side of the picture needs a frame of resilience, a positive attribute of those suffering with cancer and those helping them to fight with it as their caregivers. In the modern regime of healthcare research, it is important to acknowledge the finest and most significantly impactful factors of adjustment and adaptation for the well-being of adolescent patients and their caregivers.

The advancements in the medical field have increased the survival rate of the patients with chronic or acute illnesses. The journey from diagnosis through treatment to recovery has always been painful and difficult for both the patient and the family. And this painful journey, though it ends in recovery and strengthens the physical health, it compromises the mental health at the same time. Terms like illness behaviour and sick roles are often used by the health professionals to understand the impacts of the disease, diagnosis, and its treatment. This chapter will introduce the topic of interest highlighting its brief background, rationale, and significance of the study. There has already been substantial work undertaken on adolescents with cancer, their caregivers, and their resilient capacities. I wish to explore these resiliency capacities and their meaning in a specific cultural context which would satisfy my preference for research which might eventually be of practical value in the Malaysian health system. In spite of its significance, this area of research has been neglected, with the scarcity of research literature on the identification of the issues of adolescents with cancer in Malaysia and their caregivers as well as on the exploration of positive attributes like resilience. This provided me a context to explore this area, and my initial findings might be valuable to the Malaysian health system.

In the subsequent chapter two, a detailed review of the literature has been provided to understand what has been studied in the area and where there is a gap to do more. In chapter three, methodological aspects of the study have been elaborated on, in detail. Chapter four provides an in-depth analysis of the results and discussion,

pointing out new aspects of resilience specific to the culture and population. Chapter five is dedicated to the implications, limitations, and future research recommendations in the area.

1.1 Living with Cancer

Cancer is a generic and threatening disease. It is reported to be rare all over the world within the standard age of 0-14 years (Stiller, 2004); whilst the progression in the treatment methods has increased the survival rate for children up to 80% (American Cancer Society (ACS), 2013). However, it is an established fact that cancer as a disease brings a myriad of stressors not only for the pediatric patient but also for the family, especially the parents (Rodriguez et al., 2014). In this context, in the past decades, the research in the field of psycho-oncology has grown to a new stature. The remedial encroachment has increased the survival rate through early detection of the disease and specialised treatment, consequently turning cancer into a curable illness

1.2 Implications of Cancer on Adolescents

The diagnosis of cancer during adolescence has many physical and psychosocial impacts on the patient. It is undoubtedly a challenging situation for the adolescent suffering with cancer. Cancer has been described as a powerful life event which puts children and their families under a stressful and challenging situation. It causes uncertainty, altered and changed daily life routines, mounting physical and psychological burden, feelings of sadness and hopelessness, stress of lengthy treatment procedures, unmanageable disease symptoms, and somatic complaints (Woodgate, 2004; Phipps, 2007).

According to a report by the American psychological association (APA) (2007) and Phipps (2007), children suffering with cancer are at risk of having several behavioural, emotional, and psychosocial difficulties related to their physical appearance, body and self-image, stress of having cancer, separation from peer group and family members, and disruption in educational activities. In the pediatric cancer patients, another major implication of this disease is on their development. As children growing up with a critical disease like cancer, it has an impact on their behaviour, social, emotional and psychological development, and well-being (Woodgate, 2004; Li, Chung, and Chiu, 2010). In this regard, a pediatric patient needs to adjust and adapt too many life situations and risk factors as all these stressors are reported to have negative impact on the child's psychosocial adjustment.

If we look at the other side of the picture, adolescent cancer is reported to have positive implications on the young patients including positive self-image, positive perspective about social support, overall world view; their urge to get knowledge about their disease and its impact on their physical and psychological self which enhances their positive view about life after the encounter with crisis like cancer

(Engvall, Cernvall, Larsson, von Essan and Mattsson, 2011). However, cancer implies for negativity but now studies are unfolding the positive aspects of the disease and its treatment after diagnosis which lead the future researchers to follow the footsteps unveiling an optimistic aspect of this life-threatening illness among adolescents. As for adolescents, it's a major life event and if they are able to infer the positivity out of it while dealing with the stress of their physical and psychosocial developmental, it depicts their sense of resiliency and well-being.

1.3 Implications on Parents as Caregivers of Adolescent with Cancer

A child's critical illness like cancer has multiple and far reaching impacts on the family, especially parents who are usually the primary caregivers. The parental emotional distress, shock, and sudden disturbance in the family setup are the natural reactions towards this unanticipated life event of the child's cancer diagnosis. The high levels of parental distress are usually considered to be associated with the prolonged and frequent hospitalisation, lengthy treatment, and fear of a relapse in the cancer. It is documented in literature that the consequences of childhood cancer on parents are usually depicted in the form of four major stress reactions after getting the child's cancer diagnosis, which include: uncertainty, anxiety, depressive symptoms, and post-traumatic stress (Vrijmoet-Wiersma, 2010).

1.4 Incidence of Cancer in Malaysia

Cancer, as it is reported by the reputed organisations, is one of the principle causes of mortality worldwide. According to the World Health Organisation's (WHO) report, in 2012 there were an estimated 14 million new cases each year with a death toll of 8.2 million worldwide, which will rise to 13.1 million by 2030 (Stewart, and Wild, 2014). In Malaysia, there was no National Cancer Registry (NCR) till 2001 to estimate the incidence of cancer in Malaysians. Therefore, according to its most recent report in 2006, in peninsular Malaysia, the number of new cancer cases had decreased from 26, 089 in 2002 to 21, 773 in 2006 due to the advancement in the treatment procedures (NCR, 2006). But at the same time, when the unregistered cases are taken into account, it reveals that the risk of every Malaysian of getting a cancer diagnosis throughout his/her life is 1 in 4. According to its latest report in 2007, 18,219 new cases were diagnosed and registered in the NCR. It comprised 44.6% of males and 55.4% of females. The most commonly diagnosed types of cancer were breast, colorectal, lung, cervix, lymphoma, leukemia, ovary, stomach, and liver (NCR, 2007).

1.4.1 Incidence of Childhood Cancer in Malaysia

Overall, in the industrialised world, amongst children under the age of 15, cancer is marked as the 4th most common cause of death. In its 2009 report, WHO declared the global incidence rate of childhood cancer was 160,000 cases per year amongst children below 15 years of age, and the death rate was 90,000 per year amongst the same age group (Ferlay, et al., 2012). Fortunately, Malaysia has had the national

cancer registry since 2001 which can provide an approximate estimate of the prevalence of cancer in the childhood population. According to the latest report of the cancer registry (2007), 319 males and 220 female children were diagnosed with cancer. Here, the most frequently diagnosed cancer was leukemia between the ages 0-14 years. In male children, 48 % and in female children, 44.5 % were diagnosed with leukemia.

The above-mentioned incidence data indicated that the number of children suffering with cancer tends to be quite large and as a major part of the patient population they need physical and psychological attention. However, the particular data regarding adolescents' cancer incidence in Malaysia is not available; therefore, no particular estimate can be mentioned here.

1.5 Resilience and Adolescents with Cancer

It is evident through researches that cancer has the potential to put the patients and the family at risk of developing cognitive, behavioural, and emotional problems. However, there is a set of the population which remains intact and composed during the times of distress, and even develops resistance to fight the stressors of the illness. Resilience is such a capacity, which allows individuals to shield themselves even when there is a threat to their physical health, though these capacities are quite related to the unique characteristics of the individual and their distinctive responses towards the stressors (Cal, Reberio, Glustak and Santiago, 2015). The occurrence of chronic or life-threatening diseases like cancer has deep rooted effects on the children or adolescents, which can be mended if the resiliency capacities are encouraged and the process of developing protective factors has been facilitated. Now, it has been given importance that resilience in children suffering with cancer should be studied and explored (Ishibashi and Ueda, 2003). During the past two decades, the emphasis was upon studying resilience in adolescents about poverty, behavioural problems, and substance abuse (Stewart, Reid and Mangham, 1997); whereas, now the diagnosis, treatment, and survival rate is increasing, therefore, the interest has been shifted towards the positive effects of coping and adjustment in the pediatric cancer patients. It has been established in researches that children and adolescents suffering with cancer are normal children dealing with extraordinary life circumstances. This idea has led to put attention on the concepts of "resilience" and "coping" (Eiser, 1994). Once a child or adolescent experiences the physical and psychological trauma of cancer treatment, that child is not the same. The entire family system is forced to adjust to these new needs of the sick child and the new roles they have taken on in the family system. Resilience in childhood cancer patients was majorly studied in the 1990s (Ishibashi and Ueda, 2003). As the concept of resilience is difficult to define theoretically and test empirically, some theoretical models were developed. One of those models by Rutter (1985), focused majorly on the resilience in adolescent cancer patients.

Research continues to reveal long-term physical and psychological effects of the diagnosis and treatment of adolescent cancer. The sudden life changing identification affects not only the patient with paramount stressors but the whole family. These physical effects on the children or adolescent patients include secondary cancers, heart damage, lung damage, infertility, chronic hepatitis, and alterations in growth and development; as well, psychologically there can be impaired cognitive abilities, emotional disturbance, and psychosocial effects (ACS, 2010). Whereas, for the family, the impact is equally distressing emotionally, socially, and even financially, so the quality of the family life undeviatingly influences the quality of the life of the sick child. In this regard, it is of paramount importance that these issues of the child and the family as a unit are addressed by the health professionals.

1.6 Developmental Context and Resilience

The diagnosis of cancer during adolescence has the potential of putting them at risk of developing emotional, social, and behavioural difficulties. The time of adolescence has its unique demands and nature. The child is growing through a transition from the dependent phase of childhood to a more autonomous and independent one. Masten and Obradovic (2006) proposed that risk and protective factors have different impacts on children at different developmental stages. They suggested identifying developmentally appropriate adaptive functioning for defining resilience in children. An adolescent is trying to develop a more stable self-image, growing awareness of sexuality, and has the ability to think in more abstract terms (Roberts, Turney, and Knowles, 1998). Along with the developmental stress, the cancer diagnosis puts the added burden of treatment, hospitalisation, and the impending threats of the disease (Eiser, 1994; Lewandowska, 2013). Cosantazo, Ryff, and Singer (2009) asserted from a developmental perspective, that childhood cancer diagnosis is an “off-time” life event, which is uncertain and unplanned. The term ‘off-time’ rightly describes the damaging nature of cancer whilst it disrupts their identities as well as their physical and emotional development. This disruption at various levels is indebted to the unpreparedness for the sudden unexpected event (LeMarier, 2011). The positive psychology movement encourages inculcating the positive mental attitudes, especially in children and adolescents, for building resilience (Seligman, 2000) and facing the challenge of cancer as a threatening illness, physically and psychologically.

Adolescents and young adults with cancer have marked resilience as a process of recognising unique resources to deal with the stressors of the disease and generate positive outcomes (Hasse, 2004). In an extensive literature review by Woodgates (1999) on the resilience amongst adolescents with cancer, it concluded that stressors, protective and vulnerability factors, and outcomes are the major contributors of resilience amongst adolescents. In the literature, family support has been considered as the most important protective factor to wave off the negative effects of the cancer diagnosis and related stress and resultantly, leads to a positive healthy outcome (Enskär, Carlsson, Golsäter and Hamrin, 1997). According to Rutter (1993), resilience has its developmental perspective and each developmental stage has its

own protective factors which operate at that time. According to Rouse (2001), different types of resilience are possible at different developmental stages.

1.7 Cultural Implications of the Study of Resilience

Rutter (1993) pointed out that research on resilience should be focused on those particular processes which operate in particular circumstances for particular outcomes. It is pointed out in studies that cultural differences should be taken into consideration with two particular points in focus; firstly, in revealing the diagnosis of cancer or not and secondly, the length of the average hospital stay (Ishibashi and Ueda, 2003). This approach will improve the understanding of resilience on certain patients in certain cultures and help children to cope with cancer. According to Ungar (2004), the resilient capacity gained its uniqueness and specific qualities from cultural and the contextual framework.

As is established from the literature reviewed above, cancer as a disease is critical and burdensome in nature; and adolescence is a time period of a person's life when the individual is going through many physical, emotional, behavioural, and psychosocial changes. These transactions may be effected due to the diagnosis of cancer, in both a positive and negative manner. Secondly, research has established this notion that the adjustment and resilience processes should be studied in reference to specific cultures. The purpose of this study is to understand the concepts of adjustment and resilience in special reference to adolescence in Malaysia.

1.8 Problem Statement

The developing countries like Malaysia are growing rapidly in the medical fields and have developed assessable and affordable health systems for the citizens. In the case of serious, life threatening, and chronic illnesses, the focus of the health system is predominantly on providing medical facilities regarding disease diagnosis, treatment, and physical rehabilitation. As compared to most developed nations, the lack of allied health services like psychological help, counseling regarding adaptation to illnesses during and after treatment, and preparation for life after treatment is a major concern for the developing nations like Malaysia. Though there are centers for psychological services working mostly in the private sector, there is a gap in the services in regard to chronic and life-threatening health conditions like cancer.

There are Malaysian researchers who have investigated by exploring the impacts of various intervention strategies on the well-being of the parents of children with cancer, or some quantitative studies to explore the psychological impact of cancer on the adult patient population. The literature search made it evident that the focus of native researchers has remained on the negative impacts whilst more specifically focusing on the adult cancer patients, or in the case of adolescents, proxy reporting has been used, in spite of the considerable incidence rate of 48% in male children

and 44.5 % in female children as reported in the 2007 report of the Malaysian Cancer registry. Now, in the new age of health advancement, the international community of researchers has focused on the exploration of the positive aspects of illnesses like cancer whilst focusing on the strengths of the patients themselves and their caregivers. They are more concerned with identifying the factors which helped them to adapt positively and perform well after the illness entered their lives; whilst others are not. Resilience is one such ability which is required to be concentrated on in the case of chronic or life- threatening illnesses (Cal et al., 2015). It is also stressed in literature that the health- related phenomenon, negative or positive, should be indigenously studied in reference to the culture and resources available. In this study, resilience has remained the focus of the investigation, which is considered as a multidimensional and culture specific construct, defined distinctively by the individuals according to their cultural values, communities, and resources (Ungar, 2008). There is a serious gap in the local Malaysian literature in this regard; limited work has been undertaken on exploring the concept of resilience amongst the patient population; alongside that, there is scarcity of foundational work on exploring and understanding the concept in certain sets of populations overlooking the role of culture, community, and religious values. This existing gap has allowed me to explore this area and add a significant piece of knowledge to the adolescent health related research, indigenous and ethnic to this culture.

The current study targeted adolescent cancer patients in Malaysia and their caregivers, exploring their understanding of their lives after cancer, the way they conceptualised resilience, and gave meaning to it. To achieve this, a phenomenological research design of the qualitative research regime was employed. It facilitated well in exploring the concept of resilience as the Interpretive Phenomenological Analysis (IPA) is a well-studied and well-recommended method of analysis to study health related attributes amongst patient populations and their caregivers (Biggerstaff and Thompson, 2008). The descriptions of their lived experiences helped me to comprehend their idea of living after the cancer diagnosis and how resilience came in to help them to rebound out of the adversity of illness.

1.9 Research Questions

- What is the meaning of resilience for the adolescents with cancer and their caregivers in Malaysia as their lived experience it?
- How and why is the concept of resilience important in reference to illnesses like cancer?
- What reinforces their resilient capacities?

1.10 Objectives of the Study

1. To explore the concept of resilience amongst adolescent cancer patients and their caregivers whilst understanding their lived experiences.
2. To identify the factors which promote resilience in some sections of the target population.

1.11 Significance of the Research

The present study will be an initial step in understanding the issues of the adolescent cancer patients and their caregivers, and despite focusing only on the problem oriented approach; it will highlight the solution oriented perspective. It will bring forward the positive approach of looking at the effects of cancer, a life-threatening disease.

The results will facilitate not only the patients and their families to learn and adapt a better way of living with a crisis, but will also give a hand to the health professionals to make other less motivated and depressed patients and their caregivers lead a better adjusted life. The study highlighted a dire need to explore the health-related issues of young adolescents suffering with cancer and their caregivers. It is required to consider the positive aspects of cancer and its treatment on the patients and their families to enhance their quality of life and adaptation to new life situations. It is also suggested to further elaborate the concept of resilience in survivors of childhood and adolescent cancer survivors and their families. It is also recommended for future research work to focus on intervention services for the patients and their caregivers, to widen the scope of this area of research in the context of Malaysian culture and health care system.

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