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REVIEW ARTICLE

Resilience among Malaysian Adolescent Cancer Patients and their Caregivers: A Review

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ABSTRACT

Cancer is one of the diseases which have severe psychological and physiological implications in the affected patients, and it gets an even uglier form in case of childhood cancer that engulfs the entire household. The devastating nature of the childhood cancer causes a wave like effect which goes from adolescent to the parents/caregivers/family, making it a family disease. Along with the distressing effects and side effects of cancer the adolescents are constantly grappled with the developmental issues, whereas, family/caregivers struggle with a unique adaptation and evolution, due to the challenges posed by the disease. The current paper is a literature review of resilience among adolescent cancer patients (ACPs) and their caregivers, in Malaysian backdrop. It offers an insight into the gap in the current knowledge and highlights the need of an analysis of the concept of resilience among the targeted population in accordance with specific cultural considerations. The review primarily based upon studies targeting adolescents with the disease and their caregivers, their stressors; and processes of adjustment and coping while highlighting the cultural and religious aspect. It established the fact that in Malaysia, ACPs have hardly been studied unlike their caregivers. It's essential to consider the optimistic concepts such as resilience as a foundation stone for those who are struggling with health challenges, directly or indirectly, especially in Asian societies, while focusing on their cultures, religion and spirituality. It's the responsibility of the clinicians, researchers and health care providers to undertake the research and recommend new ways of living for the patients and those related.

INTRODUCTION

The journey from diagnosis of cancer through treatment to recovery has always been painful and difficult for both, patient and the family. The pain, fear, hopelessness, anxiety and uncertainty about future has exacerbates when the patient is a budding soul, an adolescent. The negative impacts of this immensely damaging disease are well narrated and established through research as well as through our experiences in one or the other way. Along with negative impacts, research has also been invested in the positive impacts of being a patient. The strengths of the adolescent patients and their caregivers, such as coping, adjustment, resilience, have grabbed the attention of researchers since 1900's among children with various adversities in different sets of populations and cultures (Ungar, 2005).

The current review is focused upon exploring the resilience related literature in Malaysia, among adolescent cancer patients and their caregivers. It provides an insight into the work done on the patient population and the methodological issues along with the suggestions for the future work.

Cancer------risks and challenges for adolescents and their caregivers

The experience of cancer has changed the outlook of the person altogether, it's impact is so negatively powerful that it alters not only the physical appearance of the individual but the inner self as well. The situation is more evident in the case of adolescent cancer patients and their care givers. The stressors of the adolescent cancer patients are classified as acute and chronic stressors. Acute stressors are mostly related to timely events such as pain, surgery or treatment side effects whereas chronic stressors refer to the long term complex changes and alterations in patient's life and family dynamics due to cancer (Aldridge and Roesch, 2007; Lewandowska, 2013). According to Aldridge and Roesch (2007) children with insufficient social support are more likely to have poor coping and difficult adjustment to the life after diagnosis of cancer. During the time of adolescence the individuals tend to seek for the new and wider world around them, and at this stage serious health related issues are damaging. This traumatic event affects the whole family and for this Chesler et al., (2005) termed it as a "family disease". The adolescent cancer diagnosis puts the whole set of family system in a state of turmoil. Though this state of turmoil makes all the members of the family to adjust, adapt and alter their routines and life style according to the special and extraordinary needs and demands of the adolescent cancer patient but the most intensely affected are the primary care givers, mostly the parents. During this time the family relationships are redefined not only at the individual level but also at the family and social levels. According to the National Association of Social Workers, (2014), adolescents of ages 13-19 years are mature enough to understand the challenges of cancer diagnosis, its side effects and the stress and anxieties of their parents due to their illness. They are also aware of the uncertainty of cancer, its demands and the restriction it puts on their independence, socialization and other normal activities. In case of children and adolescents with cancer, usually family/parents are the care giving source. It is important to take important steps to maintain this family support for the wellbeing of the adolescent patient and the whole care giving unit (LeMarier, 2011). The diagnosis of cancer brings with it a large pile of problems at different levels. These problems need special attention while dealing with the stress. According to LeMarier, (2011) most of the issues related to adolescents' cancer and the family stress can be sorted out though communication, but unfortunately, extreme stress wards off the individual and the family to communicate about the disease related stress. According to Eiser et al. (2001) open, direct and honest communication about the uncertainties, fears and difficulties related to cancer, helps to enhance the quality of life of patients and their families.

In the past the studies were focused on assessing the experiences and issues of a dying child and his/her family or technically saying more problem-focused (Zimmerman, 2013). The ill child was kept unaware of the illness and its effects which would increase the anxiety, isolation and depression, while at the same time parents were left alone, facing the challenging and threatening situation. In that phase they need support and encouragement to be strong enough to take care of themselves and their children as well to form a bonding between the fragmented sections of their lives post-cancer. In the past two decades the researchers have changed their focus from illness related distress, negative adaptation and amelioration to the positive aspects of illness, coping and adaptation abilities. Since 1990's there was a trend to study the individual strengths, coping, adjustment and adaptation in childhood cancer and childhood cancer survivors and the concept of resilience emerged (Ishibashi and Ueda, 2003). Resilience is a capacity which defines the "why" of coping with the traumatic, disturbing and distressing situations. According to Walsh (1996) resilience with its intrinsic eminence of bouncing back doesn't simply refer to 'breezing through' an adversity or crisis, as untouched or unaffected, instead it requires incorporating the soul of the experience into the fabric of individual and family identity and how they lead their lives. It generates a sense of optimism for future.

Resilience, a conceptual framework

It is assumed that in the past few decades there is a shift in research and service delivery from a deficit-based approach, which was all about maladjustment and psychopathologies in the face of challenges, to a strength-based approach which focuses upon healthy adaptation and positive outcomes (Hunter, 2012). And this shift gave rise to the concept of resilience. Indeed there is an ample amount of literary work already describing the damaging nature of the disease and its detrimental side effects on the adolescents and the ultimate need of intervention for them (Bleyer, 2005; Eiser et al, 2009; Albridge and Roesch, 2013). The positive psychological tools are the foundation stone of this intervention process allowing the adolescent patient to cope and adjust. Among these positive psychological tools and resources, resilience has a prominent place as a major positive health outcome. It not only allows a person to face the adversity on the front foot but also motivates to move forward in life while adapting to the situation (Rosenberg et al., 2014). However, it is difficult to identify the meaning of resilience among adolescents with cancer and their parents as its quite subjective in nature (Rosenberg et al., 2014). It is agreed by the experts that resilience is a multi-dimensional and complex phenomenon with diverse meanings in the context of circumstances, family, society, organizations, individual characteristics and culture (Southwick et al., 2014). So in this regard, it is crucial to study this complex but the useful positive health outcome phenomenon in the cancer stricken population to highlight its significance and identify the processes to enhance it.

Resilience------ defined in children and adolescents

Resilience concerns the ability to bounce back. It involves doing well against the odds, coping and recovering (Stein, 2005). It's about taking oneself out of a distressing and challenging equilibrium in all aspects of life. According to Newman (2004) resilience is comprised of three factors, and their interplay will bring the outcome in young children. They include risk, vulnerability and protective factors. Therefore he defined resilient children as those who resist adversity, manage to cope with uncertainty and are able to recover from trauma successfully.

The concept of resilience in children and adolescents has a strong background. The researchers have defined it differently according to the context of their study. In the beginning, resilient children were termed as "invulnerable children" (Gramzy, 1974). It was assumed that the resilient children remain unaffected by the adversities and not prone to any type of emotional disturbance. It is strongly agreed notion that resilience in children requires adaptation in the presence of risk situation, whereas, adaptation and well-functioning without risk and adversity cannot be considered as a marker of resilience in child (Vanderbuilt-Andriance and Shaw, 2008). In this regard, presence of a risk situation or adversity is the foremost criterion to be fulfilled to fall on the continuum of resilience.

It can be assumed that resilience in children involves a complex processes according to the child's life context, environmental conditions, resources, social, emotional and personal factors, external family and environmental factors which affects negative experiences and facilitates the positive chain reactions (Rutter, 1999; Hunter, 2012). Adaptive or competent functioning is suggested to be the outcome and vital indicators of resilience (Hunter, 2012).

Developmental context of resilience among cancer patients

Now it's been given importance that resilience in children suffering with cancer should be studied and explored (Ishibashi and Ueda, 2003). Resilience in childhood cancer patients was majorly studied in 1990's (Ishibashi and Ueda, 2003). The time period of adolescence has its unique demands and nature. The child is going through a transition from 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 todevelop a more stable self-image, growing awareness of sexuality and ability to think in more abstract terms (Roberts et al., 2001). The diagnosis of cancer in adolescence has the potential of putting them on the risk of developing emotional, social and behavioral difficulties. Along with the developmental stress, cancer diagnosis puts an added burden of treatment, hospitalization, and the impending threats of disease (Eiser, 1994; Lewandowska, 2013). Cosantazo et al. (2009) asserted from a developmental perspective, that childhood cancer diagnosis is an "off-time" life event, which is uncertain and unplanned. At this age they are developing their identities and diagnosis of cancer at this stage disrupts the developmental process altogether. These cancer related difficulties become more critical and damaging in adolescence or at a younger age due to the unpreparedness (LeMarier, 2011) and lack of knowledge. These damaging threats to the patients and those related can only be buffered through the positive mental attitudes, positive behaviors and immense social, emotional and familial support. The positive psychology movement encourages inculcating the positive mental attitudes, especially in children and adolescents, for building resilience (Seligman, 2000). Adolescents and young adults with cancer have marked resilience as a process of recognizing 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 resilience among adolescents with cancer, concluded that stressors, protective and vulnerability factors and outcomes are the major contributors of resilience among adolescents.

According to Rutter (1993) resilience has its developmental perspective and each developmental stage has its own protective factors which operate at that particular time. According to Rouse (2001), different types of resilience are possible at different developmental stages.

Resilience among the caregivers of ACP's

It is evident through researches that cancer has the potential to put the patients and the family on risk of developing cognitive, behavioral and emotional problems. However, there is a set of population which remains intact and composed during the times of distress and develops resilience in spite of life stressor of illness (Luthar and Zigler, 1991). Once a child or adolescent experiences the physical and psychological trauma of cancer treatment, that child and the family are 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. In recent literature it is made evident that along with standard oncology treatment of the patient, psychosocial health care should also be addressed not only of the patients but also the families who are in need of support (Jacobsen and Wagner, 2012). In literature family support has been considered as the most important protective factor to waive off the negative effects of cancer diagnosis and related stress and resultantly leads to a positive healthy outcome (Ensksar et al., 1997). According to Rolland and Walsh (2006), family resilience must possess flexibility with the process and ability to assign new meanings and dimensions to life after adversity.It is stated in researches that due to child's illness, if parental distress exists then its alarming and can be damaging to the quality of life of the patient, parents and all those related (Kazak and Barakat, 1997). However there are families who face the challenge showing the bouncing back characteristic of resilience and hence, resilience is a major and integral part of psychosocial health care (Rosenberg et al., 2013) of adolescent and their families.

Data sources

In this paper, the studies related to cancer and all of the people and factors dealing with it were reviewed under the key terms adolescence cancer, pediatric cancer, adolescence cancer and their care givers/ families, resilience, resilience and chronic illnesses, resilience among adolescence cancer patients and their care givers families, resilience studies in Malaysia particularly, while giving a general overview of important work done outside Malaysia. The review included both qualitative and quantitative studies from inception to the year 2013. There was no restriction upon the type of cancer studied in the researches because it would further restrict the review to even lesser number of studies.

Resilience and cancer-an overview

The extensive review of the current literature has well established the fact that adolescents face more difficulties at the multiple levels, after the diagnosis of cancer, in comparison to their counter parts at an older age. All around the world considerable work has been done in this area, while considering the cultural differences for the past decade, in fostering the resilience among different sets of populations (Iishibashi and Ueda, 2003). This is because of the myriad of developmental changes they are going through and during this time the diagnosis of cancer is extremely daunting. In this respect a recent study by Wu et al. (2013) investigated the predictors of anxiety and resilience in on-treatment adolescent cancer patients. It was a cross sectional study and used previously developed anxiety, coping and resilience scales.The results suggested that the positive and problem oriented coping skills are positively correlated with the resilience among adolescents and there is a need to enhance these characteristics among adolescent patients. In the mentioned study though the results are significant but the identification of the predictors of cancer related anxiety and resilience might remain under studied due to the use of scales, as they restrict the generation of information to the items mentioned in the scales. In comparison, a qualitative study done by Wallace, (2007) investigated the changes in physical appearance among adolescent girls with cancer, and their resilience. The study used semi structured interview for exploring the area under study. The six females of ages 14-19 years were included, all of them having completed their treatment for cancer. The collected data was analyzed through interpretive phenomenological method. The results came up with five major themes including; appearance changes, rejection of an illness identity: holding on to being normal, the meaning of appearance after cancer, increased appreciation and enjoyment of life and aspects of health care provision. Themes from 2-4 provided a more in depth view of cancer experience and its impact and their resilience. The study does have the limitation of a small sample, focusing on only one factor i.e. physical appearance, without gender variation and no on treatment patients but the survivors only which might have affected their recall of the particular events or stressors during treatment, their adaptation and adjustment to their after treatment life situation. Apart from all these limitations, the study provided a valuable data on adolescence cancer, its impact and the resilience factor among the target population, as there are quite a small number of researches in this area.

In all this messed up life situation after cancer diagnosis, as discussed above, the care givers are equally affected. The strength, warmth, and support the patient is seeking from their care giver, including parents and other family members, significant impact on their adjustment and resiliency. There are few studies which elaborated the family adjustment, coping and resilience at the time of risk. Walsh (1996) did a considerable work on the concept of family resilience and its background. Though, his work lacks the studies on the resilience of patients with medical ailments and their families.His exploration of the concept even in the different sets of population, clearly identifies the basics of the concept of resilience. He asserted that the researchers identified the significance of warmth, affection and emotional support. According to him, children's resilience to crisis situation has augmented when they had the conscious realization of being supported by the person(s) around. The concepts of family resilience and individual resilience are distinct from each other. Family resilience is the relational resilience of the family as a whole. The concept helps to confirm the notion that family resilience stands for the competence of the unit for 'self-repair'. McCubbin and McCubbin (1996) define the term family resilience as the successful coping of the families during transitions, stress and adversities. In a recent study by Kari and Marie (2008) explored the key factors associated with normal resilient families. This study can be taken as a base line of resilience as the factors mentioned in the study were collected through an extensive review of literature. Such a study can be taken as reference and guide to look upon those families who are suffering with some adversity or stress. The appreciation of the concept broadens the strength based approaches, which considers the stress and adversity not as damaging event but as an opportunity to grow (McCubbin and McCubbin, 1996; Walsh, 2006) to be explored in health related research. In this regard it has been confirmed and encouraged in researches that the concept of resilience and family resilience needs to be studied during the course of illness in the families.

In specific relation to family/ parental resilience in pediatric cancer patients, a qualitative study by McCubbin et al. (2002) is worth quoting. They focused on the identification of the family resilience factors, form the parents perspective, in the management of childhood cancer. The study followed resiliency model of Family Stress, adjustment and Adaptation (McCubbin and McCubbin, 1996) as a theoretical framework. The study came up with six resiliency factors from the study, which helped the families to bounce back from the crisis situation. They comprise; internal family strengths of rapid mobilization and reorganization, support from the health care team, support from the extended family, support from the community, support from the work place and changes in family appraisal. The limitations of the study include a monotonous sample as the study included maximum children with leukemia (because it is known for better prognosis and high survival rate); plus it includes either only the parents' perspective or of the families of the survivors of childhood cancer, and not of the directly affected child. In spite of the limitations, the study provided quite considerable evidence on family resilience and factors promoting it during childhood cancer, while highlighting the significance of child's own unique experience of the disease. Resilience is a trio of protective; vulnerability and risk factors, and their interaction brings in what we call individual or family resiliency.

Healthcare system in Malaysia

Malaysia lies in the Southeast Asian region. It's an upper middle class nation with a multi ethnic and multi-cultural structure of the society. It has the population of more than 30 million (World Population Prospects, 2015). The healthcare facilities are controlled by Ministry of Health (MOH). There are public, private and traditional healthcare services. Public sector health facilities are quite subsidized for the Malaysian citizens. Many sets of population are exempted from charges after providing letter from school or welfare departments, such as school children up to 17 years of age, economically, mentally or physically disabled or elderly citizens or charged minimally including civil and government servants and their dependents under 21 years and some public sector employees under certain agreement. However, they have to wait for a long time in the queue. On the other hand the private sector has speedy but very expensive health facilities to offer In Malaysia, this dual layer health system of public and private health care units are providing services to the consumers. Private health centers are centered in urban areas with quick and perceived high quality health services while public health care units are more focused on rural areas and offering affordable primary and secondary health care facilities (Lim, 2002; MOH, 2013).

Incidence of cancer in Malaysia

Cancer is considered to be a leading common cause of deaths in Malaysia. There are estimated 37,400 people per year newly diagnosed with cancer (Ferely et al., 2012). As far as adolescent or pediatric population is concerned no official data is available. Lim (2002) gave an overview of the pediatric cancer incidence according to the types in Malaysia (Table 1).

Research on cancer patients in Malaysia

During the exploration for the study, it has been established that cancer is more common among adolescent males than in females. The children under 16years are treated for cancer at the county's biggest and most equipped pediatric cancer institute in Hospital Kuala Lumpur (HKL). However, researchers seem to be more interested and inclined towards exploring the psychological effects of cancer on the adult population as compare to pediatric or adolescent population. The disease is undoubtedly distressing in any age group, varying in intensity and its implications. Through the extensive literature survey on Malaysian cancer patients and the research conducted on them, it revealed that though there are number of studies which are catering the cancer patients including male and female adult patients but it lacked the research on the pediatric or adolescent population.

The trend is changing in Malaysia also to concentrate and highlight the positive aspects of being a cancer patient. A study conducted by Schroevers and Teo (2008) explored the posttraumatic growth in Malaysian cancer patients and its effects on psychological distress and coping strategies. It was a quantitative study and claimed in results that positive coping strategies facilitate posttraumatic growth. There are few studies focusing on the pediatric cancer patients and the issues related with the illness, but they usually gather data about the children through the proxy report. There is an important study conducted on Malaysian adolescents to tap their knowledge and beliefs about cancer it's risk factors and treatment as well as the relationship between knowledge and various demographic variables. It was a cross sectional study conducted on ten public schools of Shah Alam. The sample of 261 students was collected through random sample selection method. Their beliefs and knowledge about cancer was assessed

Table 1: Rate of common childhood cancer types in Malaysian population (per million basis)

Types of cancer	Per million
Leukemias	35.0
Tumors of the brain and spinal cord	13.9
Lymphomas	5.8
Neuroblastoma	4.9
Gonadal and germ cell tumors	4.1
Kidney	4.0
Soft tissue sarcomas	3.7
Retinoblastoma	3.6

(Lim, 2002)

through an indigenous questionnaire focusing on demographics including age, race, religion, SES, parental marital status and their own smoking status, information related to cancer, informants beliefs about the cancer treatments and their efficacies and finally the potential healthy behaviors which can reduce risks of cancer. The results indicated that the adolescents from higher socioeconomic class and highly educated parents had better knowledge and awareness of cancer and its treatment. Along with this they also suggested that adolescents living in the urban areas have more assess to the cancer treatments and awareness campaigns than those in the rural arrears. This study provides a baseline regarding the cancer knowledge and awareness issue among the young adolescents, though the study possessed a small sample from one particular capital city of the state but at the same time its contribution to the research knowledge is significant. Apart from this other major and prominent studies in Malaysia related to cancer, are primarily focused on the caregivers of the adolescent or pediatric patients or adult cancer patients are the main respondents. In this scenario, there is a lack of such studies which are tapping the inner voices and issues of adolescent cancer patients in both quantitative and qualitative research. In a study (Othman et al., 2011) the wellbeing factors of parents of pediatric cancer patients were explored. In that study, though the main respondents were parents but there was a domain in which psychological distress of children due to their illness was also explored through parental report. In the last few decades, studies and researches done on quality of life and wellbeing of pediatric patients have also encouraged the child's self-report to ensure the accuracy of the response. Therefore it is recommended to rely on self-report of children when it's possible to do so. In Malaysia, most of the work on cancer patients has been conducted through quantitative research. However, there are two major pieces of research done on the adult cancer patients through the qualitative mode of research. Farooqui et al. (2011, 2013) conducted qualitative studies to explore Malaysian cancer patient's perspective about cancer and its treatment, followed by their perspectives on the cancer screening. The results depicted interesting findings, such as in the first research on the perspectives about cancer and its treatment, the majority of patients relate the diagnosis to the God's will. All the informants were interviewed and reported that the reason for delay in treatment was the fear of side effects. However, the patients reported to consider conventional therapies as effective due to their scientific background. In their second study they investigated the Malaysian patient's perspective about cancer screening and early diagnosis. The informants were interviewed through the semi structured interview. The results indicate that most of the patients were not even aware of any such screening and some have heard about the screening but had never gone for it due to lack of knowledge and financial restraints. The researchers came up with suggestions to make the situation better for the patients by educating them and making screening facilities accessible to all. These mentioned researches have done a somewhat detailed ground work on part of the adult cancer patients. As, cancer diagnosis itself is quite distressing and to understand it's repercussions, it is obligatory to do the same ground work on all the age groups to understand their issues. In a recent study by Ezat et al. (2012) highlighted the steps needed to improve the quality of life among Malaysian cancer patients. It discussed the limitations in the field of oncology services such as late diagnosis, insufficient treatment facilities etc. and suggested that the currently adopted ways by the government and the non-government organizations (NGOs) require strengthening to get the maximum positive results. This study provides a good foundation in the area of exploring positive and adaptive behaviors of cancer patients.

In the pediatric set of cancer patients, considerable work has been conducted by Othman. In a recent study she and her colleagues developed a guided imagery relaxation audio for children in local language (Malay). The audio has been pilot tested on the 20 pediatric oncology patients showing the positive and effective results. It was hypothesized that that relaxation imagery audio can be used in Malay as an intervention tool for pediatric cancer patients' ages 7-15 years diagnosed with different types of cancers. The results indicated that all the participants approved the imagery script and background music as enjoyable and relaxing (Othman, 2013). This study provides a solid ground for the future researches in the field of psychological interventions for pediatric cancer patients. Though this work on pediatric cancer patients is quite valuable but at the same time it can't replace the need for exploring the basic issues and hidden strengths of the patients as they are going through the toughest phase of their lives and still making positive out of it. She has also developed a psychological educational program for parents of children with cancer. It is pilot tested till date. The study engaged 79 parents, to choose either in the control group (n=38) or intervention group (n=41). The control group received the standard care whereas the intervention group received 4 sessions of 50min each along with the standard care. The additional sessions provided the information on childhood cancer and coping skills. The results suggested that increased knowledge about childhood cancer reduced their anxiety and improved their coping skills. However, the results were not significantly different for both the groups (Othmanetal, 2010). Although the study contributed well in understanding the need of psycho-education activities for caregivers, but it still needs to be done on a larger group to validate the particular set of psycho-educational program. While investigating and exploring the effects of pediatric cancer on the parents, the group presented a Meta analytic review (2009), focusing on the psychological interventions for parents of children with cancer. They investigated 16 studies that had used meta-analysis techniques. The results suggested that the psychological interventions do help to develop positive coping skills in the parents to deal with the distressing time phase of their child's illness. The above mentioned two studies highlighted the need of psycho-education and psychological interventions for the caregivers, while undermining those, directly affected. The group has also done a project on identifying the factors related to wellbeing of parents of children with cancer (Othman et al., 2011). It was a cross sectional study with 79 participating parents. The participants were assessed on the basis of demographics accompanied by the questionnaires measuring their knowledge of the disease, and the activities they bring up to enhance child's coping abilities. The results indicated that higher education level, more knowledge about cancer, child being an outpatient and high socio economic status with more activities performed with children all contributed well in enhancing their wellbeing and adjustment and reducing their anxiety and stress. The major studies conducted in Malaysia regarding resilience in healthcare and cancer patient population is summarized in Table 2.

All the above mentioned studies highlighted the vitality of the psychological interventions, knowledge about the disease, availability of the treatment facilities for adjusting and accepting the life threatening challenge with a positive outlook. Here is the point where the process of "resilience" comes in action. It seems to be this dynamic process of resilience which helps, both the pediatric patient and the care givers to bounce back and adapt to the situation in a much more positive manner.

Conclusion and recommendations

In the light of above mentioned literature and discussion, the fact is well established that there are very few studies on resilience in Malaysian research literature and all of them have targeted the general adult populations, nurses at work place, adult patient population (Azlina, 2010; Othman and Nasurdin, 2011; Misajon et al., 2006) but not the adolescents or children suffering with cancer. This requires extensive baseline researches to dive into the thoughts, ideas, issues and experiences of the adolescent cancer patients and their care givers.

This paper may show only the tip of the ice berg of unheard issues of the adolescent cancer patients and their care givers allowing us to look into the existing wide gap in the knowledge in the Malaysian context; it highlights the solution oriented perspective. It brings forward the positive approach of looking at the effects of cancer, a life threatening disease.

The results of this literature review will facilitate the health professionals and researchers to focus on the issues of the target population while adopting a solution-focused positive approach of investigation and later intervention. The review helps us as researchers, to emphasize on the cancer related difficulties of these growing souls and their suffering families. Though a considerable work has already been done in the world but in Malaysia such studies are lacking for adolescents and their caregivers, simultaneously.

As it is established from the literature reviewed above that 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, behavioral and psychosocial changes. These transitions may be effected due to the diagnosis of cancer in both positive and negative manner. Secondly, research has established this notion that resilience processes should be studied in reference to specific cultures (Ishibashi and Ueda, 2003). The aim of this paper is to focus and highlight this gap in the current literature on resilience in special reference to adolescent cancer patients and their caregivers in Malaysia.

Future prospects

The paper is an attempt to highlight the gap in the current knowledge and existing literature, with special reference to Malaysia. There is a need of the time to address this gap in an effective manner as the cancer diagnosis among these young souls is growing higher, and so does its social, psychological and familial burden. In order to move forward and set a framework, an extensive research project is required to cater the queries related to the illness related difficulties, their positive solutions as suggested and adopted by the patients and their families. It's quite essential to develop a counseling protocol for the use of health care providers, to ensure the wellbeing among other patients and their care givers. The study of resilience and related concepts needs to be encouraged in the South East Asian region in order to explore its cultural implications.

Table 2: Summary of prominent Malaysian literature on cancer population

Title	Method	Sample	Significant findings	Reference
Knowledge and beliefs of Malaysian Adolescents regarding cancer	Cross-sectional research	261 public school students. Mean age 14.0yrs both male and female	• Malaysian adolescents possessed a moderate level of knowledge regarding cancer its risk factors and treatment. • Adolescents with the highly educated parents have more health awareness. • Adolescents living in the urban areas have better assess to the health facilities and cancer awareness campaigns.	Al-Naggar et al. (2015)
A qualitative exploration of Malaysian cancer Patients' perceptions of cancer screening	Qualitative research. Semi structured interviews.	20 Adult cancer patients	• Four themes; awareness of cancer screening, perceived benefits of cancer screening, perceived barriers of cancer screening and cues to action. • Most of the patients lack the knowledge about cancer screening. • Financial constraints were a major barrier. • Suggestions were provided to improve the knowledge of healthy individuals about screening.	Farooqui et al. (2013)
Improving QOL among cancer patients in Malaysia	Commentary	Reports, review and government documents	• Incidence of cancer has increased in Malaysia along with the survival rate. • Issues affecting the QOL of patients include financial constraints and lack of knowledge. • Informal care giving strategies, o physical and psychological levels. • Development of National Control Program in 1990 facilitated a lot in improving the QOL of cancer patients.	Ezat et al. (2012)
Guided Imagery and Relaxation Audio for Children with Cancer: Development and Evaluation	Experimental research design	23 participants. 5 adult cancer patients 18 pediatric cancer patients	• Twenty participants approved the imagery, translated in Malay language, as relaxing. • Study established the fact that psychological interventions are necessary for pediatric cancer patients.	Othman et al. (2013)
Factors related to parental well-being among parents of children with cancer	Cross sectional study	79 Parents of pediatric cancer patients	• Higher cancer knowledge, high income and high education related to reduced stress and anxiety. • Parents on inpatients taking chemo reported high anxiety and stress than outpatient parents.	Othman et al. (2011)
A qualitative exploration of Malaysian cancer patients' perspectives on cancer and its treatment	Qualitative research. Semi structured interviews	20 Adult cancer patients	• Disease is the God's will. • Conventional therapies are more preferred. • Fear of side effects is the main reason to delay treatment. • However, perception changed after treatment due to effective ways to manage side effects.	Farooqui et al. (2011)
Psychological Interventions for Parents of Children who have Cancer: A Meta-Analytic Review	Meta analytic study	16 studies related to the psychological interventions for the parents of children with cancer	• Incidence of cancer has increased in Malaysia along with the survival rate. • Issues affecting the QOL of patients include financial constraints and lack of knowledge. • Informal care giving strategies, physical and psychological levels. • Development of National Control Program in 1990 facilitated a lot in improving the QOL of cancer patients.	Othman et al. (2009)

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Authors' contribution

ZA conceived the idea for the review and wrote the manuscript. MAT contributed in thorough revision and write up of the manuscript. HA and SA facilitated in analyzing the relevant literature. All authors read and approved the final manuscript.

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