

**PARENTAL CHALLENGES IN CAREGIVING FOR CHILDREN WITH
CANCER**

by

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**Thesis submitted in fulfillment of the requirements
for the degree of
Master of Social Science (Social Work)**

May 2013

ACKNOWLEDGEMENTS

I would like to acknowledge, with thanks, the role that the following people had played in the production of this thesis.

I thank God Almighty. I thank Sri Ranganatha Swami for his guidance.

I thank the participants of this study who gave their fullest support and for trusting me with their information. Without their participation, this study would not have materialized.

I thank my parents, Rajaratnam and Prema and also my sister Shanthini for their constant encouragement and support throughout the two years of my research. A special thanks to Suganthi as well.

I thank Assoc. Prof. Dr. Azlinda Azman who guided and encouraged me to complete this study especially when I felt like giving up.

I thank the medical social workers from the Jabatan Kerja Sosial Perubatan of Penang Hospital for their support to conduct this study. A special thanks to Faridah.

I thank my friends at the National Cancer Society, especially the Relay for Life Penang organizing team who had given me various opportunities to learn about cancer.

I thank my friends, Kevin, Muthu, Raagav, Jay, Sanjay, Shoba, Ayoub and Sivagami.

I thank fellow students and staffs of School of Social Sciences, Universiti Sains Malaysia for their support and advice throughout the research.

I would like to dedicate this thesis to my late grandfather, Mr. Ramasamy, who showered me with love and care since my early age.

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LIST OF ABBREVIATIONS

CWC	Children with Cancer
ACS	American Cancer Society
ACSO	American Society of Clinical Oncology
NCI	National Cancer Institute

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CABARAN YANG DIHADAPI OLEH IBU BAPA DALAM MEMBERI JAGAAN KEPADA KANAK-KANAK YANG BERPENYAKIT KANSER

ABSTRAK

Objektif kajian kualitatif ini adalah untuk meninjau pengalaman yang dilalui oleh ibu bapa yang memberi jagaan kepada kanak-kanak yang menghidapi penyakit kanser, terutamanya dari aspek cabaran dan strategi penanganan cabaran. Kajian ini dijalankan ke atas lapan orang responden yang dipilih dari Hospital Pulau Pinang. Pemilihan responden kajian adalah berdasarkan dua kriteria, iaitu a) tahap kefungsi pesakit dan b) kumpulan etnik keluarga pesakit. Skop kajian ini meliputi: a) cabaran-cabaran yang dihadapi oleh pemberi jagaan, b) sokongan sosial yang diterima oleh pemberi jagaan, dan c) cara menangani cabaran-cabaran yang dihadapi oleh pemberi jagaan. Hasil kajian mendapati bahawa pemberi jagaan dalam kajian ini menghadapi cabaran yang sama seperti yang dilaporkan dalam kajian-kajian literatur sedia ada. Walau pun begitu, terdapat beberapa pandangan berbeza yang telah diutarakan oleh para responden dalam kajian ini. Antaranya, cabaran yang dihadapi oleh para responden tidak hanya terhad kepada kewangan, tetapi juga meliputi penjagaan dalam bentuk perubatan; penjagaan emosi kepada anak-anak mereka yang mempunyai kanser; serta penjagaan terhadap anak-anak mereka yang lain. Persepsi responden terhadap sokongan sosial yang mereka terima dan juga strategi menangani cabaran-cabaran yang dihadapi juga dikupas untuk lebih memahami pengalaman mereka dalam memberi jagaan kepada anak mereka yang mempunyai penyakit kanser. Hasil kajian turut mengenalpasti keperluan sokongan sosial yang secukupnya untuk para ibubapa selaku penjaga. Pekerja sosial perubatan dilihat mempunyai prospek dalam

usaha membantu mengurangi emosi-emosi negatif yang timbul dalam kalangan responden melalui intervensi-intervensi yang relevan.

PARENTAL CHALLENGES IN CAREGIVING FOR CHILDREN WITH CANCER

ABSTRACT

The objective of this qualitative study was to explore the experience faced by the caregivers of children with cancer in terms of challenges that the illness brings along and their employed coping strategies. The study was conducted on eight respondents who are primary informal caregivers being purposively selected from Penang Hospital. The selection was based on two criteria, namely a) functional level of the patient and b) ethnic background of the family. The scope of the study includes: a) challenges faced by the caregivers, b) social support received by the caregivers, and c) their coping strategies. Study findings revealed that the caregivers faced similar challenges as those from the literature. However, there are dissimilar opinions from the respondents which were discussed in this study. Among others, the challenges faced by caregivers were not limited to financial, but also involve medical caregiving for their ill child; emotional caregiving for their ill child; and caregiving for the siblings of the ill child. Respondents' perception towards social support that they received and their coping strategies were also explored to better understand the emotional journey throughout their caregiving trajectory. Findings from this study also points out that adequate social support are vital for the caregivers. Thus, medical social workers have the prospect to reduce the respondents' negative emotions through relevant interventions.

CHAPTER 1

INTRODUCTION

1.1 Background of Study

Studies done in many countries recognize childhood cancer as a source of extreme stress on caregivers, especially parents due to the life-threatening nature of the disease and its painful, lengthy and intensive treatment (Dahlquist et al., 1994; Hoekstra-Weebers et al., 2001; Norberg et al., 2004; Bayat et al., 2008). Cancer can be considered to be a “family disease” because not only the patient but the key members of the family who are providing care are affected by the disease, particularly when it becomes a chronic illness (Blum et al., 2001). In the case of childhood cancer, the effects of cancer are evidently severe for the child, the parents and other family members (Last & Grootenhuis, 1998).

Since the 1960s, advances in treatment techniques as well as supportive care have created dramatic improvements in the survival of CWC which have shifted the focus of pediatric oncology to include the quality of life of the child, their siblings, and parents (Wiener et al., 2006). As family’s psychological adjustment impinge on a child’s emotions, psychological or medical care are generally not made available to children without the involvement of any adult family members (Kazak, 1997).

Family members experience numerous challenges and obstacles living with and caring for their child who is diagnosed with cancer. These challenges could be, but not limited to adjustment to child’s invasive procedures during treatment, management of their child’s emotional reaction as well as their own, and loss of income and out of pocket expenses related to cancer care (LaMontagne et al., 1999;

Svavarsdottir, 2005; Limburg et al., 2007). These challenges have been recognized to contribute towards an enormous amount of stress that affects the family who has CWC.

1.2 Statement of Problem

In the United Kingdom, 1,367 cases of cancer were diagnosed in children in 2007 and an average of 300 cases of death from childhood cancer was also reported in the three year period of 2000-2002 (Cancer Research UK, 2009). Furthermore, “although cancer in children is relatively rare and survival rates are now good, death in childhood after infancy from other causes in the UK is now so rare that cancer is still an important cause of death in older children” (Ibid.). In the United States, approximately 8,600 new cases of cancer are diagnosed in children younger than 15 each year or less than 1% of all malignancies (Pizzo, 2001).

Not only children from the west but also countries in the east such as Malaysia are affected by this malady. The population of children below the age of 15 for the year 2004 is 6.419 million and it represented 33% of overall population in Peninsular Malaysia for that year (National Cancer Registry [NCR], 2008). According to Lin, in a study done from 1993 -1995, the crude incidence rate for pediatric malignancies in Malaysia was 77.4 per million children aged less than 15 years (as cited in Gerard, 2002). Lin has also highlighted that the Malaysian Cancer Registry Report indicates 37 in 100,000 children are at risk of developing cancer with a crude incidence rate of 0.000007 (as cited in Azizah et al., 2009).

The survival rate of CWC in Malaysia and all over the world has now improved by advancement in medical technology (Ibid.). In a study done in the

United States, it was found that the survival rate of pediatric cancer survivors has increased from 58% for patients diagnosed in 1975-1977 to 80% for those diagnosed in 1996-2004 (Jemal et al., 2009). Increase in survival rate signals the need for caregiving for the patients as they will be battling the disease for a longer period of time. Most of the CWC are given care by their parents. Thus, it is utmost important for a research to be conducted on them because they are the primary informal caregivers to these children.

Parents undergo enormous amount of stress upon receiving the news of their child's diagnosis of cancer. The stress experienced will not only be detrimental to themselves but also to their sick child. In a study done to investigate the probable anxiety and depression among 177 family caregivers of cancer patients in Malaysia, it was found that the prevalence of probable anxiety and depression were 48.6% and 29.4% respectively (Ambigga et al., 2005). Parents who are unable to cope with their anxiety and depression would certainly not only be unable to provide effective emotional and tangible support to their children but they might in fact transfer their distress to their children. Research by Wagner et al. (2003) supports the notion that children would be more affected by parental distress if their parents are unable to cope with it as their study found that an increased parental distress was significantly associated with greater child depressive symptomatology. Depression in these CWC may pose a potential danger to their lives. Suthahar et al. (2008) supports this statement through his research which found that depressed cancer patients had almost four fold greater risk of dying than non-depressed patients.

There are several factors that contribute towards the well-being of parents whose children are diagnosed with cancer. They are caregiving challenges, social

support, and coping methods. These factors determine the degree of emotional distress faced by them.

Challenges such as financial burden due to cancer diagnosis are one of the contributing factors to caregiver's stress. Research by Montgomery (1985) illustrated that those with relatively low socioeconomic status are assumed to report a higher burden, and subsequently a poorer health (as cited in Nijboer, 1998). Cancer is a disease which may impose a heavy economic burden on its patients and their caregivers. A substantial amount of money will need to be spent on patients, especially more on those who do not own any health insurance. These expenses are for treatment, transportation and care.

A child who is diagnosed with cancer will need to undergo phases of treatment depending on the type and stage of cancer (American Cancer Society [ACS], 2010). Caregivers would need to bear the treatment charges for their child at hospital or medical centres. The patients may also need special food and supplements which would be an additional expenses to their parents. Moreover, they will also have to bear the transportation fee for their child's regular treatment in hospital, which may require the child be present at the hospital every week for few years. Caregivers need not only spend money, but also their time as these children needs special care. Children whose needs create increased time and care demands on their family will make it more difficult for caregivers to be an employee (Kuhlthau, 2005). It would be difficult for caregivers to seek for employment when the child is undergoing treatment for cancer.

Childhood cancer can leave a significant impact on caregivers. As treatment for cancer is generally long term, caregivers would need social support from their

social networks to enable them to cope with their caregiving distress. Social support is defined as a network of family, friends, neighbors, and community members that is available in times of need to give psychological, physical, and financial help (National Cancer Institute, n.d.). Caregivers who are left to deal with their cancer stricken child will need some form of comfort for themselves because caregiving task can be stressful. Therefore, they tend to turn to their network of family and friends to ease their emotional and physical burden.

Coping with their care receiver's disease is one of the difficult tasks for care providers to undertake. Most of the caregivers would not be able to cope well with their care receiver's disease due to lack of support and knowledge. An effective coping method helps caregivers to overcome stress and anxiety. In turn, they would be able to provide a better care for their care receiver who is diagnosed with cancer. Coping strategies can be defined as actions that people can take to master, tolerate, reduce, or minimize the effects of stressor, and they can include both behavioral strategies and psychological strategies (Cicarelli & Meyer, 2006). There are two ways of coping that can help people to cope with stress. They are problem-focused coping and emotion-focused coping. According to Mitchell et al. (1983):

Problem-focused coping refers to task orientation, i.e. strategies used to solve a problem, reconceptualise it or minimize its effects. Emotion-focused coping strategies refer to person orientation which basically includes emotional responses, self preoccupation and fantasizing reactions (as cited in Ramli, 2008, p. 1).

Coping strategies of caregivers of CWC will determine their quality of life as well as

quality of their caregiving.

A research is thus needed to explore the challenges that contribute to negative emotions that these caregivers face due to caregiving challenges and also the roles that social support and their coping strategies plays in helping to cushion their level of perceived negative emotions. The researcher wanted to see whether the caregivers in this study differ in their perception and satisfaction towards social support received and coping methods employed in dealing with childhood cancer diagnosis and treatment. The result of this research would be useful to the Ministry of Health and the Ministry of Women, Family and Community Development to understand more about medical social workers and the roles that they can potentially play in cancer care. Social workers who specialize in oncology will then be able to guide patients with cancer and their family members through the ordeal.

1.3 Research Questions

1. What are the sources of stress of caregivers of children with cancer in Penang Hospital?
2. What are the perceptions towards the social support received by caregivers of children with cancer in Penang Hospital?
3. What are the coping strategies employed in providing care by the caregivers of children with cancer in Penang Hospital?

1.4 Objective of the Study

1. To identify the sources of stress of caregivers of children with cancer in Penang Hospital.

2. To analyze and understand the caregiver's perception towards the social support received.
3. To examine and identify the coping strategies of caregivers of children with cancer in Penang Hospital.

1.5 Significance of the Study

In Western countries, parents of CWC are found to be facing numerous issues (Svavarsdottir, 2005; Nicholas et al., 2009; Wijnberg-Williams et al., 2006; Norberg & Boman, 2008). In Malaysia however, not much study has been done to highlight the challenges that these parents face in dealing with their children's cancer. Among the few studies done, Azizah et al. (2009) has highlighted the importance of her study which claims to be the first of its kind in pediatric oncology setting at a Malaysian government hospital suggesting that the field is still largely remains unexplored. Thus, this study is of great importance for the literature of pediatric oncology social work in Malaysia. In addition to that, the study of impact and burden of cancer care on family caregivers according to Clark (2001) are one of the most important areas for psychosocial oncology research that should be undertaken in the next decade.

Furthermore, caregivers of childhood cancer patients as a minority group among other cancer caregivers as well as economically distressed groups will be the target population so that variations or adaptations needed to minimize caregiver distress related socioeconomic diversity can be determined. This study will potentially guide interventions aimed to assist childhood cancer patients and their caregivers to increase their preparedness to deal with the overall care process and for interventions aimed at reducing avoidance based coping among family caregivers of the patients. It

will also identify the potential positive responses to providing care to CWC and how such responses may cushion the effect of negative caregiving outcomes.

1.6 Limitation of the Study

The respondents chosen were not exhaustive and are limited to caregivers, who are the parents of CWC seeking treatment at Penang Hospital. Data collected are dependent upon honest responses by the respondents on the instruments utilized in the study.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The purpose of this study was to investigate the challenges experienced by caregivers of children diagnosed with cancer. The study also investigated on the social support received by these caregivers during their caregiving process. The need to understand how the caregivers cope with a child's diagnosis of cancer and how that issue impacts the caregivers' psychosocial health is a fundamental issue in the functioning of the family system.

This literature review is divided into four categories beginning with an introduction into the medical aspects of childhood cancer followed by studies focusing on challenges of caregivers of CWC, social work in healthcare and theories that were used in this study. Studies in this part of review on parents as caregivers of CWC will focus on parental psychological reactions, parental coping, social support and socioeconomic impact.

2.2 Medical Aspects of Childhood Cancer

Cancer is one of the major health problem in Malaysia (Gerard, 2002) and many other parts of the world (Jemal et al., 2009). Cancer is not one disease state but rather many, all characterized by the presence of an uncontrolled (i.e., malignant) proliferation of a certain cell in the body (Rosenthal, 2001). Thus, the growth of a cancer cell is different from normal cells and instead of dying, cancer cells continue to grow and form new, abnormal cells (American Cancer Society [ACS], 2011). Cancer cells can also invade (grow into) other tissues, something that normal cells cannot do. Growing

out of control and invading other tissues are what makes a cell a cancer cell (Ibid.).

Cancer is not only a disease of adults. It also affects children and even infants. However, there are marked differences between childhood and adult cancer. Cancer is generally a rare disease among children unlike in adults (Cavdar et al., n.d.).

According to Pizzo and Poplack (1996), another notable difference is the initial response of most childhood cancers to current therapeutic modalities, resulting in a significant number of cures (as cited in Pizzo, 2001). The cause of their responses can be known when we look into the nature of cancer of children and adults. Cancers of epithelial or differentiated cells predominate in adults and cancers of embryonal or developing cells and tissues predominate in children because pediatric malignancies are characterized by a high growth fraction or a higher rate of tumor cell multiplication, which enables the tumors to increase in size more quickly than in many adult malignancies (Ibid.). Unlike in adults, pediatric malignancies tend to be generalized or systemic illness at the time they are diagnosed (Ibid.).

The types of cancer that develop in children are also different from the types that develop in adults. The table 1 below presents the cancers that predominate in children by age and site:

Table 1 <i>Predominant Pediatric Tumors by Age and Site</i>				
Tumors	Newborns (<1 yr)	Infancy (1-3 yr)	Children (3-11 yr)	Adolescent & Young Adult (11-21 yr)
Leukemias	Congenital Leukemia AML AMMoL	ALL AML CML, juvenile	ALL AML	AML ALL
Lymphomas	Very rare	Lymphoblastic	Lymphoblastic Burkitt's	Lymphoblastic Burkitt's Hodgkin's
Central Nervous System	Medulloblastoma Ependymoma Astrocytoma Choroid plexus papilloma	Medulloblastoma Ependymoma Astrocytoma Choroid plexus papilloma	Cerebellar astro- cytoma Medulloblastoma Astrocytoma Ependymoma	Cerebellar astrocytoma Astrocytoma Craniopharyngioma Medulloblastoma

			Craniopharyngioma	
Head & Neck	Retinoblastoma Rhabdomyosarcoma Neuroblastoma	Retinoblastoma Rhabdomyosarcoma Neuroblastoma	Rhabdomyosarcoma Lymphoma Multiple endocrine neoplasia	Lymphoma Rhabdomyosarcoma Multiple endocrine neoplasia
Thorax	Neuroblastoma Teratoma	Neuroblastoma Teratoma	Lymphoma Neuroblastoma Rhabdomyosarcoma	Lymphoma Ewing's Sarcoma Rhabdomyosarcoma
Abdomen	Neuroblastoma Mesoblastic nephroma Hepatoblastoma Wilm's tumor (>6 mos)	Neuroblastoma Wilms' tumor Hepatoblastoma Leukemia	Neuroblastoma Wilms' tumor Lymphoma Hepatoma	Lymphoma Hepatocellular carcinoma Rhabdomyosarcoma
Gonads	Yolk sac tumor of testis (endodermal sinus tumor) Teratoma Rhabdomyosarcoma (sarcoma botryoides) Neuroblastoma	Rhabdomyosarcoma Yolk sac tumor of testis	Rhabdomyosarcoma	Rhabdomyosarcoma Dysgerminoma Teratocarcinoma, Teratoma Embryonal carcinoma of testis Embryonal carcinoma & endodermal sinus tumors of ovary
Extremities	Fibrosarcoma	Fibrosarcoma Rhabdomyosarcoma	Rhabdomyosarcoma Ewing's sarcoma	Osteosarcoma Rhabdomyosarcoma Ewing's sarcoma
<i>Notes:</i> ALL, acute lymphocytic leukemia; AML, Acute myelogenous leukemia; AMMoL, Acute myelomonocytic leukemia; CML, chronic myelogenous leukemia				

Table 1: Predominant Pediatric Tumors by Age and Site. Pizzo et al. (2001)

The table 1 above presents the cancers that predominate in children by age and site.

Some cancers which are observed soon after birth (e.g. neuroblastoma or retinoblastoma) suggests a genetic basis for their occurrence, while other malignancies appear to peak during early childhood (e.g., acute lymphoblastic leukemia), or tend to arise during the periods of growth and development associated with adolescence (e.g., osteosarcoma, Ewing's sarcoma, and rhabdomyosarcoma) (Ibid.).

An example of childhood cancer is neuroblastoma. Neuroblastoma is a tumor that develops from tissues that form the sympathetic nervous system (the part of the nervous system that controls body functions, such as heart rate and blood pressure, digestion, and levels of certain hormones) (PubMed Health, 2008). In most patients, the initial symptoms are often vague and the neuroblastoma has already spread before

their first diagnosis (PubMed Health, 2008; Macmillan Cancer Support, 2010).

2.2.1 Test and Treatment

A child who is suspected by a physician to have cancer will undergo a screening process to determine the presence of cancer in his/her body. The process requires the child's medical history (including health habits and past illnesses and treatments), physical examination (an exam of the body to check general signs of health, including checking for signs of disease, such as lumps or anything else that seems unusual), laboratory tests (samples of tissues, blood, urine or other substances in the body taken and tested), imaging procedures, and genetic tests (National Cancer Institute [NCI], n.d.). According to the NCI (n.d., p. 1) :

“Screening for cancer does not only help to determine the possible existence of active cancer cells in the body, but also brings along potential harm to the patient. Although most cancer screening tests are noninvasive or minimally invasive, some involve small risks of serious complications that may be immediate or delayed which includes false-positive test results, over diagnosis and false-negative screening test. Thus, these potential harms must be considered against any potential benefit of screening for cancer”.

Once a child is diagnosed with cancer, physicians will formulate a treatment plan. Surgery, chemotherapy, radiation therapy, immunotherapy and stem cell transplantation or bone marrow transplantation are the types of general treatment that are used as part of a child's treatment plan (American Society of Clinical Oncology [ASCO], 2010). Treatment for cancer patients have now improved due to advancement in medical technologies. According to the ACS (2010), because of

advances in treatment, about 8 out of 10 children treated for cancer survive at least 5 years and most of these children are cured. New techniques such as plaque method for retinoblastoma (childhood eye cancer) are now being used in an attempt to save the eyes of a young child compared to only conventional chemotherapy and laser treatments (Washington University School of Medicine, 2010). These treatments catered for childhood cancer like any other cancer depends on the type of cancer, the size and the location of a tumor, whether the cancer has spread and the child's overall health (ACSO, 2010).

Most of the children who are diagnosed with cancer are treated with chemotherapy. Chemotherapy is treatment in which its drugs attack cells that are quickly growing and dividing. There are several ways of administering chemotherapy drugs to a patient. These drugs can be given orally (usually as pills), intravenously (infused through a vein), intramuscularly (injected into a muscle) or subcutaneously (injected under the skin) (ACS, 2011). The drugs work because cancer cells grow and divide faster than most normal cells, but some normal cells also divide quickly, such as the cells in the bone marrow that make new blood cells, the cells lining the inside of the mouth and stomach, and the hair follicle cells (ACS, 2011). These dividing cells are the ones most damaged by chemotherapy and this may cause side effects during treatment, such as low blood cell counts, nausea, diarrhea, or hair loss (Ibid.). Severe side effects can lead to loss of time at school for the children, loss of time at work for the caregiver, and additional office visits to the doctor; all of which contribute both to the annual costs of cancer (Dewan et al., 2010). Furthermore, chemotherapy treatment can cause not only short term side effects, but also some long term side effects such as cardiopulmonary effects, endocrine effects, and

neurocognitive effects. These effects cause damages to the heart, lungs, thyroid, renal, bladder, genitourinary tract, GI tract and liver and many other parts of the body (Aziza, 2010)

Apart from chemotherapy, radiotherapy has become an important treatment modality in pediatric oncology (Haeberli et al., 2008). According to the ACS (2010, p.1):

“Radiation therapy or radiotherapy uses a high-energy radiation to kill cancer cells. Radiotherapy is most useful if some of the main tumor is still left after surgery or if completely removing the tumor would mean loss of an important organ, like the eye or bladder, or would be disfiguring. This method of treatment can also produce unwanted short-term side effects such as fatigue, increased number of infections and effects on skin areas that received radiation which ranges from hair loss and mild sunburn-like changes to more severe skin reactions”

Those who are undergoing radiotherapy are also susceptible towards several late effects of the treatment. In children, irradiation prior to full development of various tissues can result in failure of normal development and the severity of growth retardation relates primarily to the age at treatment, the dose of radiation used, and the location treated (Pizzo & Poplack, 2006).

Surgery remains a critical component in the multimodal therapy of childhood cancer (Shamberger et al, 2006). Children diagnosed with cancer would need surgery at some point of their treatment. There are several reasons for children to undergo surgery as a treatment option. They are for the purpose to diagnose their cancer (predict the benign or malignant nature of tumor via preliminary incisional biopsy),

delivery of drugs (surgical placement of a catheter for intraventricular administration of anticancer drugs) or as a primary treatment (removal of tumors for cases such as hepatoblastoma, a malignant liver tumors in infancy and early childhood) (Pizzo & Poplack, 2006). However, advances in surgical technique have allowed surgeons to successfully operate on a growing number of patients with less invasive operations in order to preserve as much normal oral cavity structure and function as possible (Oral Cancer Foundation, n.d.).

2.3 Challenges of Parents of Children with Cancer

The diagnosis of cancer impacts not only the patient, but also the entire family. The family's perception of pain and suffering which is associated with cancer places a greater fear in them. Family members especially parents of the child with cancer are burdened with caregiving challenges which include for example giving emotional support to the child with cancer and to other children in the family, difficulties of getting employed, financial problems, helping their children to comply with the treatment plan and coping with the effects of treatment (Svavarsdottir, 2005; Kuhlthau et al., 2005; Lauria, 2001). The purpose of the research on parents of CWC was to explore these psychosocial and emotional challenges that caregiving for CWC brings.

2.3.1 Financial Challenges

The influence of financial challenges in the level of stress of caregivers of cancer patients have been long documented in several studies done. Studies have indicated that caregivers with coping, social, and material resources are less likely to suffer deleterious consequences as a result of caregiving demands, while those with few

resources are at elevated risk (Van Ryne et al., 2011).

A study was done to examine the financial challenges on families caring for a child with cancer. The researchers conducted a semi-structured interview with 28 French and English families with a child diagnosed with cancer in the last 10 years. It was found that families who care for a child with cancer incur considerable costs during the diagnostic, treatment, and follow-up care phases of the disease. Four major themes were identified as contributing factors for these expenses which were necessary travel, loss of income because of a reduction or termination of parental employment, out-of-pocket treatment expenses, and inability to draw on assistance programs to supplement or replace lost income. In addition, the researchers also found that many of the decisions with regard to the primary caregiver were gendered as mothers are the one who terminated or reduced work hours compared to fathers (Miedema et al., 2008).

Another study was done to investigate the impact of childhood cancer on parental employment and sources of income in Canada. A sample size of 111 self-report questionnaires was completed by families with children diagnosed with cancer. The study revealed that 64% of mothers and 16% of fathers left their job after their child's diagnosis. The large majority of parents who left their jobs were away for less than 1 year (65% of mothers; 78% of fathers) and nearly all were able to return to the same job if they chose to do so (80% of mothers; 89% of fathers). According to the researchers, there was considerable change in sources of income between the time of diagnosis and survey with more families relying in employment insurance, social assistance or other financial support at diagnosis. However, reliance on sources of income other than salary decreased with time since diagnosis. Thus, it was found that

the diagnosis of childhood cancer may cause an important but short-term impact on the employment and income sources of affected families (Limburg et al., 2007).

2.4 Parental Psychological Reactions

There have been different types of parental psychological reactions to childhood cancer which were highlighted by researchers. The most common reaction studied is emotional stress or distress such as depression, anxiety and hopelessness. Sadness and feelings of depression are normal and understandable reactions of parents to their child's cancer diagnosis (Lauria, 2001). The depressive symptoms that parents may exhibit include, but not limited to, a persistent sad, anxious or empty mood, feelings of hopelessness or pessimism, feelings of guilt or helplessness, decreased energy, difficulty concentrating or making decisions, restlessness, and insomnia or oversleeping (Vrijmoet-Wiersma et al., 2008).

Researchers have used several measures of psychological well-being, including instruments such as General Health Questionnaire (to measure nonpsychotic psychiatric disorder) and PTSD Checklist (to screen individuals for posttraumatic stress disorder) and found that childhood cancer parents are at higher risk to exhibit psychiatric symptoms (Dockerty et al., 2000; Manne et al., 1998). These symptoms along with parents distress proved to vary as a function of time from diagnosis with parents of more recently diagnosed patients presenting a higher level of symptoms than parents of long-term survivors (Norberg & Boman, 2008).

Several studies have shown that parents are profoundly affected by their children's cancer. In a study done to determine the depression, anxiety, hopelessness, and perceived social support levels of 94 parents of CWC, the authors found that

parents of CWC experienced anxiety, depression and hopelessness. Mothers in particular, have more anxiety and feelings of hopelessness than fathers because they spend more time with their ill children (Bayat et al., 2008). Thus, parents, particularly those who spend more time looking after their ill child are more effected by the diagnosis of cancer.

Another study was done by Wells et al. (1990) to look into emotional responses of 26 parents of cancer patients. It was reported that 69% of the parents were under strain, 57% felt scared, 11% felt blue and 2% of them felt angry or panicky since the diagnosis of cancer of their children. Psychosocial responses which were obtained in this study revealed that 88% of the respondents reported that fatigue always interfered with their normal activities, while 43% have trouble sleeping throughout the night (Wells et al., 1990). Parents have also been found to exhibit symptoms of PTS (Post-traumatic stress), such as difficulty in making decisions, difficulty in remembering, difficulty concentrating upon their children's diagnosis of cancer (Santacroce, 2002).

Parental psychological reactions are found to not only affect themselves, but also their children. Emotionally stressed parents who are providing care for their ill children may ultimately transfer their negative emotions to their children. Negative emotions of parents might have an intense effect on their children as these children are capable of detecting non-verbal cues that the parents exhibit. Haivland and Lelwica (1987) found that 10-week-old infants could imitate their mother's facial expressions of happiness, sadness, and anger (as cited in Hsee et al., 1991).

Drotar (1997) from his review of 57 published studies after 1976 on the relationship between the psychological adjustment of children with chronic illness and

parental and family functioning articulated that more adaptive family functioning and parental psychological adjustment were associated with positive psychological adjustment while less adaptive family relationships (e.g., greater conflict and maternal psychological distress) consistently predicted problematic adjustment. Thus, parent's psychological reactions may further affect their children who are ill if necessary measures are not taken to help them cope with their distress.

2.5 Social Support

Appropriate social support is important for parents in facing their children's disease, especially life threatening ones such as cancer. According to Cobb (1976), social support is defined as information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligation. The term "social support" is generally not used in everyday conversation, rather it is referred to as "she is always there when I need her", or "she is the only person I can trust and confide in", or "I get lots of help from my neighbors", or "he is someone I can always count on". Socially supportive behavior indicates that people have a reciprocal relationship that they genuinely care about one another and that the needs of others equals or surpasses one's own needs (Bruhn, 1934).

Numerous typologies of social support measures have been suggested by researchers in the literature of caregiving. House and Kahn (as cited in Cohen, 1998) suggested three categories of support measures: social networks, social relationships, and social supports. Social networks refer to measure deriving from formal network theory, including measures of network size, density, multiplexity, reciprocity, durability, intensity, frequency, dispersion, and homogeneity (Ibid.). Social

relationship measures assess the existence, quantity, and type of existing relationships. Finally, social support measures assess resources provided by others with various measures assessing type (e.g., emotional, informational), source, quantity, or quality of resource (Ibid.).

Pedro et al. (2008) in a study titled “Social support and families of CWC: An integrative review”, reviewed fifteen articles of research conducted between 1996 and 2006 which were sourced from published reviews from PubMed, Web of Science, Cinahl, PsycInfo and LILACS. They found three themes in the studies, which are a) social support and trajectory of cancer, b) social support to healthy siblings, and c) social support to fathers and mothers of CWC. A total of 684 articles were searched revealing 15 articles that met the author’s initial criteria. The articles researched were from eight countries and predominantly from the United States. As for study design characteristics, six of the articles used a quantitative methodological approach, four used qualitative methodological approach, two experience report and three literature review.

The authors indicated that diagnosis and/or relapse of the disease tend to be the most difficult phase for the families of CWC. The families tend to receive adequate social support in this phase, but the reported support decrease over time due to the lengthy duration of the treatment. Social support is important for them till the end of the treatment, whether it means cure or death.

The authors have also investigated the social support received by healthy siblings of CWC. According to their study, there are several factors that contribute to the answers given by healthy siblings such as their culture and closeness of relations between them and their sick counterpart. These healthy children are found to be

vulnerable towards psychosocial problems if adequate support is not given to them.

Parents of CWC are not left out in the author's study. In general, men are found to suffer more from isolation and receive less social support than women. This may be because women demonstrate greater anxiety which is why they seek more support than fathers. Offering social support to these parents however should be done independent of gender. Sources of support offered to these clients include partners, family, friends, employees, hospital team, religious organizations and other parents experiencing the same situation.

2.6 Parental Coping

When a child is diagnosed with cancer, the parents are left to cope with the emotional stress that the disease brings along. They are further burdened with the responsibility of caregiving for their ill child. Coping refers to behavior that protects people from being psychologically harmed by problematic social experience, a behavior that importantly mediates the impact that societies have on their members (Pearlin, & Schooler, 1978). In the literature of childhood cancer on the other hand, the term coping is used to mean either "the ways people try to handle stress" (i.e. certain strategies) or "how they get along" (i.e. adjustment, adaptation) (Norberg et al., 2004). Most studies on coping among parents of CWC focused on coping strategies used in relation to stressors of their child's disease, for example on "how parents perceive their situation as well as their coping efforts" (Last & GrootenHuis, 1998; Patistea, 2005), "the relationship between coping strategies and anxiety/depression" (Norberg et al., 2004) and "the impact of childhood cancer on parents and description of their way of coping it" (Van Dongen-Melman et al., 1998).

Coping strategies that parents use may change or vary across circumstances for example, as an initial response to their children's cancer diagnosis, especially when emotional arousal is high, parents might cope with the stressor by using avoidant strategy. On the other hand, parents may employ approach strategies when they are dealing with chronic stressors, especially where vigilance or action are necessary (Dahlquist et al., 1994). Regardless of the coping strategies that parents may employ, an effective coping behavior will help them to come to terms with their distress.

LaMontagne et al., (1999) examined parent's primary stressor before their child's invasive procedure, coping strategies used to manage the stress, level of distress their children experienced during each phase of procedure and whether parent's coping modes were associated with their children's distress in 20 CWC and their parent. Approximately half of the children were girls (55%, n= 11), and the participating parents were primarily mothers (90%, n = 18). The authors utilized the Ways of Coping Questionnaire (WCQ) to assess the parent's coping behaviors and the Observation Scale of Behavioral Distress (OSBD) to measure eight operationally defined behaviors that reflect the child's distress. Parent's primary stressors were identified as uncertainty about parent role and anticipating the child's distress during the procedure. Although parents used both emotion-focused and problem focused strategies for coping with their primary stressors, they primarily relied on emotion-focused strategies. Children experienced the most behavioral distress during the procedural phase. The parent's coping modes were not associated with their children's distress, but children of parents whose primary stressors was uncertainty about parent role had higher distress than children of parents whose primary stressor was

anticipating the child's distress. These findings related to parent's stressors, their coping strategies, and their children's distress was consistent with previous research.

Studies in social work literature have looked into identifying illness related coping and adaptation framework (Mailick, 1979). One of such is a framework adapted to childhood cancer. In this framework, Lauria, (2001) have categorized family's adaptational tasks in stages of childhood cancer with description of each stage and a listing of the challenges relevant to them as shown in table 2 below:

Stage I	Diagnosis and Initial Treatment <ul style="list-style-type: none"> • Acquiring and processing knowledge and information • Providing emotional support to infant, child, or adolescent • Assisting patients with the physical aspects of disease • Expressing and managing emotional reactions to diagnosis and treatment • Adapting family life to balance the needs of all members • Attending to relationships within and outside the family • Mobilizing essential social supports and other resources • Learning to function in the health care system • Facing uncertainty and loss of control • Searching for meaning
Stage II	Treatment when Remission is Sustained <ul style="list-style-type: none"> • Addressing changing informational needs • Sustaining hopefulness through chronicity and crisis periods • Assisting the patient with side-effects, body image, self-esteem, schooling, and changes in personal aspirations • Mastering feelings regarding child or adolescent's disease and treatment experiences • Fostering patient's normal growth and development • Maintaining satisfactory family functioning • Dealing with reimbursement issues, government program regulations, or legal rights • Securing and using social and emotional support • Anticipating the completion of treatment
Stage III	Treatment when Disease Recurs <ul style="list-style-type: none"> • Coping with emotional responses evoked by disease recurrence • Processing information and participating in decision-making about possible new treatments • Assisting child or adolescent to understand and accept recurrence and cooperate with new plan for treatment • Regulating hopefulness about outcome
Stage IV	Progressive Disease and Death <ul style="list-style-type: none"> • Coping with emotional responses to disease progression and eventual death • Assisting the patient with physical deterioration, discomfort, and pain • Maintaining adequate family functioning • Preparing the child, siblings, and other family members for impending death • Reshaping hope to focus on the good events of each day • Helping the child or adolescent live until death occurs • Making arrangements for funeral or memorial services • Ending formal relationships with team members

	<ul style="list-style-type: none"> • Grieving and mourning the loss of child or adolescent • Finding meaning and purpose on life without the child's presence
Stage V	<p>Treatment Completion and Survival</p> <ul style="list-style-type: none"> • Managing the conflicting emotions of completing treatment • Adjusting to any long-term effects of treatment • Acquiring information about issues and resources relevant to survivorship • Resuming "normal" individual and family life • Arranging and maintaining appropriate lifetime follow-up for the patient

Table 2: Family Adaptational Tasks in Stages of Childhood Cancer (Lauria, 2001).

2.7 Social Work in Healthcare

Social work in health care has been established for more than 100 years and has developed into a major sector of the profession in countries around the world (Auslander, 2001). In their early days, social workers have been helping people get their basic needs met by understanding that physical health is strongly affected by a lot of things such as where a person lives, education, employment and emotional well-being (Fildes, 2006). Today, social workers provide services across the continuum of care and in various settings such as public health, acute, and chronic care settings in which they provide a range of services including health education, crisis intervention, supportive counseling, case management using behavioral techniques, linkage to community resources through effective screening, sound psychosocial assessment (NASW, 2005; Blum et al., 2001).

Social workers in health care have been rendering their services to help patients and their family members to cope with psychosocial challenges brought by the patient's chronic, acute or terminal illnesses. They bring the perspective of understanding the whole person and the environment in which they live as a crucial component of managing care (Fildes & Cooper, 2003). In operating from a person-in-environment perspective, social workers recognize that an individual cannot be understood apart from the multifaceted context of her or his environment (Kondrat,