University of Basrah
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Assessment Of Sociodemographic Factors, Psychological And Financial Stress In The Iraqi Families Of Children With Cancer

A Research project was submitted to the counsel of the nursing college, the university of Basra as a partial fulfillment of the requirements for the degree of B.S.C in nursing science

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CHAPTER ONE

INTRODUCTION

1.1 Introduction

Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020, or nearly one in six deaths. According to WHO in adult The most common cancers are breast, lung, colon and rectum and prostate cancers [1]. And in children Each year, an estimated 400 000 children and adolescents of 0-19 years old develop cancer. The most common types of childhood cancers include leukemia, brain cancers, lymphomas and solid tumors, such as neuroblastoma and Wilms tumors [2].

Cancer is a condition where some of the cells of the body begin to divide uncontrollably and spread into surrounding parts of the body, destroying healthy neighboring tissues. Normally, body cells divide to form new cells to replace old or damaged cells as a natural process. In cancer, new cells begin to form rapidly even when they are not needed. They form growths called tumors. As these new cells continue to divide without stopping, some of these cancer cells break off and through the blood (or lymph) travel to other parts of the body and form new tumors. [3]

1.2 Symptoms and Signs of Cancer

1.2.1 Early Symptoms

20 Early Symptomsat the earliest stage cancer gives no sign or symptoms by which we cannot indicate the disease. Moreover, the symptoms or signs are shown in harm condition. Some common symptoms that may occur with cancer are as follows [4]

1. Persistent Cough or Blood-Tinged Saliva.
2. A Change in Bowel Habits.
3. Blood in the Stool.

4. Unexplained Anemia.
5. Breast Lump or Breast Discharge
6. Lumps in the Testicles.
7. Change in Urination
8. Persistent back pain.
9. Unexplained weight loss.
10. Stomach pain and nausea.
11. Bone pain.

1.2.2 Late Symptoms

These symptoms are depending on cancer type, location or where the cancer cells have spread.

1. Change in bowel or bladder habits.
2. Obvious change in the size, color, shape, or thickness of a wart or mole.
3. Indigestion or difficulty in swallowing.
4. Change in size, shape, color or thickness of mole.
5. A sore throat that does not heal.
6. Hoarseness.
7. Thickening or lump in the breast, testicles, or elsewhere Other signs or symptoms may also alert you. These include the following:

I. Unexplained loss of weight or loss of appetite.
II. Nausea.
III. Vomiting.
IV. Fatigue.
V. Unexplained low-grade fevers may be either persistent or not.
VI. Recurring Infections
VII. Pain in the bones and other body parts.

1.3 Types of Childhood Cancer

The types of cancer that are common in children are not the same as those most oftenfound in adults. According to WHO statistics published in 2021 leukemia was the most common type ofcancer in children under 19 years of age 40 percent of allcancers in Caucasian children were leukemia [1].

The most common types of cancer in childhood [5]

1. Leukemia: the most common leukemia, acute lymphocytic leukemia (ALL).
2. Central nervous system cancers. The second most common type of cancer in children aretumors of the central nervous system (CNS) including the brain.
3. Neuroblastoma. is one of the most common forms of childhood solidtumors, typically occurring in very young children.
4. Lymphoma is cancer of the lymphatic system.
5. Hodgkin's and non-Hodgkin's lymphoma.
6. Wilm's tumor. Is a cancerous growth that originates in the kidneys.
7. Bone cancer. The majority of childhood bone cancers result from metastases from othercancers.

1.4 Causes of Cancer

There are many causes which may cause cancer in different body parts like mainly 25-30% deaths are due to tobacco consumption,10% of deaths are due to poor diet, obesity, lack of physical activity excessive drinking of alcohol or other facts include certain exposure to ionizing radiation, environmental pollutants, and infection. About 15% of cancer in the world is due to some infections like hepatitis b, hepatitis c, human papillomavirus infection, helicobacter pylori, and immunodeficiency virus (HIV), Epstein - Barr virus [6-8]. These factors are at least partly responsible for changing the genes.

1. Inherited genetic defects from patient's parents are also responsible for 5-10% of cancer.
2. Cancer is caused by the interaction between genetic factors and 3 categories of agents which we consume externally including:

i. **Physical Carcinogens**: Ionizing radiation such as radon, ultraviolet rays from sunlight, uranium, radiation from alpha, gamma, beta, and X-ray-emitting sources.
ii. **Chemical Carcinogens**: Compounds like n-nitrosamines, asbestos, cadmium, benzene, vinyl chloride, nickel,
iii. **Biological Carcinogens**: Infections from certain bacteria, viruses, or parasites and Pathogens like human papillomavirus, or Epstein-Barr virus, hepatitis B and C.

1.5 Aims of the study

1. collect a data about family coping with pediatric cancer from family members.
2. document the relations between stressful life events and changes in outcomes for parents and healthy siblings of long-term pediatric cancer survivors.

3. explore the stress levels of parents caring for a child with cancer in order to identify the psychological needs of parents in this environment.
4. explore how mothers and fathers stress levels might differ.
5. Understand how financial stress affects family cohesion as a whole.
6. Examining the relationship between cancer stress and financial stress present within families coping with a cancer diagnosis and treatment.
7. explore how family cohesion and adaptability with cancer disease of her children.

CHAPTER TWO

LITERATURE REVIEW

2.1 Pediatric cancer is stressful for the entire family

It is an unpredictable and uncontrollable stressor that puts the diagnosed child, his/her family members, and the family as a whole at risk for adjustment difficulties [.9,10].The patient experiences a loss of control over his or her life. Early on, these children often experience social isolation, stigma, and at least temporary loss of normal activities including school [11].

Survivors of childhood cancer have experienced a myriad of stressful life events that are generally not shared by their age mates. Not only have they coped with the uncertainty and fear that surrounds a cancer diagnosis, but they have also experienced numerous invasive and painful medical interventions, and have intermittently been kept out of school or away from their friends due to hospitalization or decreased immune functioning [12]. They are often exposed to painful medical procedures. They can suffer significant cosmetic changes such as hair loss (13). Even more distressing are permanent physical changes that are functional in nature such as the loss of a limb or treatment-related cognitive impairment [14,15].

When parents are confronted with a pediatric chronic condition diagnosis, their perception about the illness and its treatment are important predictors of parental adaptation [16,17]. One of the most distressing aspects of pediatric cancer is the uncertainty that comes with the diagnosis.Adolescents and young adults (AYAs) with cancer are particularly vulnerable to distress as a result of the intersection of disease and developmental stage. AYAs face unique challenges related to physical and cognitive development, identity, body image, autonomy, and employment [18,19].

Experience of pediatric cancer is very difficult for the patient. According to Barbarin, the experience often makes a lasting impact. He notes that even long after treatment has ended, cancer survivors can react to life stress in an exaggerated manner. When a child is diagnosed with cancer, parents must mobilize the resources necessary to meet the demands of the situation. They must find suitable medical care for their ill child.

Parents must find the time and financial resources to meet treatment requirements.For a patient who receives a diagnosis of cancer, the financial impact of this diagnosis can be significant. The magnitude of the resulting financial burden is determined by a multitude of factors, including household income, socioeconomic status, insurance status, and extent of disease. Causes of cancer-related financial stress are multifactorial. Treatment-related costs can be substantial, including costs of chemotherapy, radiation, and surgery, as well as home health care and travel to treatment centers [20].

A large body of research on social support and health documents that emotional, logistical, informational, and financial support from personal networks enhances the coping options available to people as they manage a serious illness [21].

Considering the outrageous costs associated withcancer care, it is clear to see how financial stress can add to cancer stress on the family, especially if the family is in a lower socioeconomic class or a part of a minority population [22,23].

This financial stress can, like cancer stress such as coping skills, worry, grief, shame, etc., cause family members to adopt new roles in order to keep the family system functioning [22]. They must find environmental supports to help take care of any other children and they must find the internal resources to cope with the physical and emotional upset caused by this traumatic experience. Parents of pediatric cancer patients have reported a wide variety of problems associated with the cancer experience. These include mood disorders [24], problems with sleep, marital difficulties, [25], distress related to employment and finances [26], and problems in social relationships [16]. Cancer causes families to adapt to changes in routine, roles, and finances [27].

The current cancer burden affects everyone in the family system, and each individual's response to those stressors has an impact on the roles and cohesion of the familysystem’s roles and cohesion [29].

According to Kazak and Nachman (1991), having a child with a life threatening illness is one of the most stressful events a parent can face. Indeed, according to the family psychology literature [30]. Children are embedded in a family, and within families, individual family members influence each another. This idea is also embedded within various family-systems models often applied to chronic illness populations [31]. Patients and parents are not the only family members who face a significant amount of cancer-related stress. Healthy siblings of cancer patients also experience a tremendous amount of distress as the family deals with cancer. Siblings spend a great deal of time thinking about theirill brother or sister and these thoughts cause sadness [32].

Siblings are often isolated from their families [33] andexperience a lack of support from their parents [16]. Healthy siblings often become angry and those feelings frequently turn to guilt [34].

The research on pediatric cancer has shown that it is stressful for the entire family. Researchers have been investigating the way individuals cope with stress for some time.The decreased attention from parents, as well as the stress from dealing with the above changes, can cause much anxiety in siblings. In fact, one study reported that nearly 65% of siblings experience some sort of psychological problem following the diagnosis. Knowing that the diagnosis of cancer for a child can be an overwhelming stressor for the entire family, the pediatric nurse is obliged to include care for siblings as a part of their commitment to the philosophy of family centered care [35,36].

With the reality of high-acuity patients and nursing shortages, one may wonder if pediatric oncology nurses have time to observe psychosocial, emotional, or behavioral changes among the family members of their patients. Although prior research has documented the significant needs of siblings, few have documented the perspective of pediatric oncology nurses in terms of their recognition of the needs of siblings or the interventions they have used to meet those needs. Thus, the purpose of this qualitative descriptive study was to address the following research questions:

Originally, the research focused on the number and intensity of stressful life events. This research established a small consistent link between the number and intensity of stressful life events and health related outcomes [37]. A more recent formulation of how individuals cope with stress has focused more on subjective experience [38].

Subjective experience in coping research refers to relying on each participant to determine the valence and intensity of a stressor. This is in contrast to the life event approach of Holmes and Rahe (1967) that used an established scale of stressor intensity. The inclusion of subjective experience was intended to account for individual differences in outcomes across different people experiencing the same stressful event. This approach has met with only limited success [39].

The typical approach to studying coping with a phenomenon such as pediatric cancer is to ask each participant individually how he or she coped with a specific event or how he or she copes in general. Coping is then used to predict outcomes for the individual. However, theorists such as Minuchin (1974, Minuchin & Nichols, 1993) suggest that in a family, stressful life events experienced by one member can have a profound effect on other family members [40].

McCubbin has developed a theory of family stress and coping that is consistent with this observation. McCubbin's approach borrows from the theoretical formulation of Lazarus (18) in that it relies heavily on the subjective experience of family members. The family-focused approach uses family-based measures for assessment of stress and coping. Cancer caregivers typically spend more hours per day providing care, provide more intense care over a shorter period of time, and are often more likely to incur out-of-pocket expenses than caregivers of individuals with other chronic illnesses [41].

Typically, measurement involves asking one member to report about the perceptions and experiences of the entire family. For example, mothers would be asked to report on family coping and this report would be used to predict the outcomes of family members. However, a focus at the family level misses important information about how the individual members deal with stressful events. Recently, research has attempted to find a middle ground between focus on the individual and focus on the entire family. This method expands on the existing methods by including perceptions of other family members' coping along with the coping reports of the individual. In other words, instead of relying on only one member's perception it asks, for example, both members of a couple to report their own coping as well as how their partner coped with an event. This method has been used with some success in predicting relationship satisfaction in couples [42] and to predict the mental health of a sample of older cancer survivors [43].

This approach improves on the use of individual self-report and the approach that uses one family informant to report on all family members by including the reports of multiple informants on the constructs of interest.The main objective of this study was to collect data about family coping with pediatric cancer from multiple family members. Not only did each member report on his or her owncoping, each person also was asked to report on other family members' coping. Both self-reportand report-of-other coping were used to predict mental and physical health outcomes. This studyalso documented the relations between changes in stressful life events andoutcomes over timefor parents and healthy siblings of long-term pediatric cancer survivors, information lacking inthe existing literature.

The literature review covers several pertinent areas of research. The reader is given a brief review of the more common cancer types suffered by children and treatment methods. This is followed by findings from the literature related to the stressors, distress, and outcome predictors for patients, parents, and siblings coping with pediatric cancer. The review provides a brief summary of relevant stress and coping theory. Lastly, a short presentation of my own recent work that formed the foundation for the current study is presented.Most pediatric oncology literature agrees that being aparent of a child with cancer is an emotionally stressfulevent [44,45].

Previous studies have showed that parentsof a child with cancer are involved in a long term therapywith their child [46].The development of coping and emotion regulation skills reflects the coordination and interplay of processes of social, cognitive, affective, and brain development over these developmental periods. Further, coping and emotion regulation skills play a central role in transdiagnostic models of preventive interventions and psychological treatments for a range of psychological problems and disorders [47].

Cancer in children has a strong impact on parent functioning. Parents of children with cancer initially report higher emotional distress levels and more psychosomatic complaints than norm populations [48]. The treatment of cancer is frequently the source of the most physical distress in cancer sufferers [49].Several studies have also found that higher levels of parental stressors on the pediatric inventory for parents (PIP)were related to higher levels of psychological distress in parents of children with cancer[50,51].

Cancer is a family experience, and often family members have as many problems coping with it as does the diagnosed patient. The family goes through different stages of adjusting to the disease. The emotional reactions may include anger, resentment, guilt and adjustment pain, and may or may not lead to the acceptance of the disease [52].

The family may feel in suspension between fear and hope for the treatment result. The chronic phase of the disease may last for months or even years including periods of treatment and remission. It is also the time when the family slowly returns to its routine life. In some families the end of chemotherapy or radiotherapy is recognized as the end of the disease itself.

They may thereby impose a pressure on the patient to pick up his/her old responsibilities, behave healthily, and stop pondering on the disease, which should remain in the past. This pressure to ‘come back to life as it was before’ can create an uncomfortable situation for the patient who may not yet feel strong enough to resume full activity or who needs his/her family to still support him/her. Other families, fearing or not yet knowing whether the patient is or is not healthy, may fall into overprotection, thereby hindering the patient’s social rehabilitation or putting him/ her in a position in which he/she feels unneeded or isolated from family life. The recovery phase is also fraught with psychological problems. First of all, there is always the threat that the cancer can come back.

The family have to constantly face the fear that there could be a recurrence, and every check-up brings a tension that the tests could detect new carcinogenic cells. Secondly, some treatment processes bring long-term effects on the health of the patient, i.e. organ dysfunctions or persistent conditioned reflexes, which can be a source of stress or negative psychological conditions both in the patient and his/her family.

Thirdly, having a close relative with cancer always puts a burden on the offspring in terms of genetics. In these ways cancer always stays in the family, forcing it to live in its shadow. The end of the life phase is the most stressful for the family members [53,54].

They often have to change their family daily life and some of their roles and responsibilities [48,51]. Parents have been found to be psychologically affected by their child's diagnosis, time since diagnosis, side effects of the treatment and child's health status. Additionally, parents have reported burden in their employment and financial status, their family relationships, caring for the other children and they feel guilty sometimes. Although these stressors were found to affect mothers and fathers parenting children with cancer, mother and fathers were found to have different levels of perceived stress.

carried out a systematic review into the factors related to parental health and wellbeing when caring for a child with cancer and identified that five main areas were found to contribute to psychological health of the parents: family social and economic characteristics, child characteristics, caregiver demands, self-perception, and coping [44].

2.2 Stressors Related to Pediatric Cancer

Regardless of the method, the process of killing cells inevitably results in undesired side effects. These side-effects cause both short and long term consequences with which both the patient and family must cope [55,56]. Investigating the methods used by families to deal

with the stress caused by pediatric cancer was an important goal of this study.

2.3 Stressors Facing Pediatric Cancer Survivors

Despite the advancements made in the techniques used to treat cancer and thecorresponding increased rate of survival, cancer and its treatment are not without considerablecosts. Some of the most significant difficulties related to coping with childhood cancer are caused by the side effects of the treatment [57]. Cancer therapy side effects are divided into two categories: early and late effects. Early and late impacts are both physical and psychological in character, and they vary based on a variety of factors such as the type of cancer, the child's age upon diagnosis, and the type of treatment received [58].

2.4 Early effects

Physical effects. Cancer treatment can cause a variety of immediate physical problems that the patient and family must face. These early effects can include loss of a limb or other forms of disfigurement, loss of hair, pain, nausea, diarrhea, constipation, fatigue, headaches, mouth and/or stomach ulcers, weight gain or loss, weakness, loss of coordination, nerve damage, increased sensitivity to the sun, heart damage, or skin rashes. Additionally, children who undergo cancer treatment often experience a protracted absence from school, at least temporary loss of peer relationships, and extended absence from home and family. If cancer related distress in the child becomes chronic, it may often lead to avoidant behaviors, difficulty readjusting to school, and future worries about their health [59].

2.5 Psychological effects

The early physical effects almost always lead to psychological distress. Obviously, the loss of a limb and separation from loved ones is traumatic for anyone. However, significant changes in life circumstances can be especially difficult for children. For pediatric cancer patients, common psychological reactions to early physical symptoms and side effects include depression, anger, fear, guilt, anxiety, and a loss of self-esteem [55,58].Cancer diagnoses not only affect the behavior of the child with cancer, but also their well siblings. Siblings of pediatric cancer patients are vulnerable to increased irritability, mood swings, agitation, increased aggression, yelling, and crying [59].

Emotional distress is another common adverse psychological outcome in pediatric cancer patients and their family members. Distress in the cancer patient may result from the child’s internal feelings of losing control and their feeling of loss associated with the lack of social interactions with peer and siblings [59,60].

Cancer is considered to be an extremely stressful experience for the ill child but also for his or her family. Most studies have found consistent results that children and adolescents who reported the health consequences of treatment for malignancy also had less positive psychological outcomes [61,62].

Cancer survivorship represents process of living following a diagnosis of cancer, regardless of how long a person lives. It is a concept used by many health care professionals and cancer patients to understand physical, social, psychological, and spiritual impact of cancer on quality of life.

Many research had been conducted to assess survivors' quality of life regarding health status, emotional distress, fertility, school achievement, social and family relations, spirituality and other psychosocial elements. This study reports on quality of life in survivors of childhood cancer as measured by psychometric instruments of post-traumatic stress symptoms, post-traumatic growth, social adjustment and quality of life scale questionnaire [63].

Some medical data related to quality of life (ie. treatment outcomes) were also assessed. For some children these reactions are temporary; as physical functioning returns, the psychological difficulties also remit. For example, a child who looses all of her hair can experience an intense feeling of loss. As her hair returns, feelings of loss tend to subside. However, for some children, their losses are not temporary and they must find new ways of living with the permanent physical changes caused by cancer and its treatment. For example, a child who looses a limb or suffers some other significant disfigurement is faced with a very difficult task in adjusting to undesired life circumstances [60].

2.6 Late Effects

Not all of the effects of cancer treatment are known at the time that the treatment is given. Late effects are those complications that arise later, sometimes years after the cancer treatment has ended. These late effects can cause a great deal of stress for families dealing with pediatric cancer [60]One reason that all of the effects of cancer treatment are not immediately known is thatcertain organ systems are not fully developed at the time that treatment is given. This makes itimpossible to determine what effect, if any, the treatment has had on these yet undevelopedsystems. Two organ systems that seem to be especially vulnerable to late effects are thereproductive system and the central nervous system, especially the brain [61].

2.7 General physical effects.

The treatment of cancer can cause significant physical changes that last a lifetime. Mulhem and his colleagues surveyed 107 male and 76 female survivors of pediatric cancer who had been free of cancer symptoms for over two years. These authors found that 65% of this sample had some cosmetic abnormalities while 37% reported some form of functional distress [62].

Sterility is a possibility for cancer survivors.The present study sought to understand the impact that having a child undergoing or having undergone medically invasive procedures (e.g., chemotherapy, radiation, surgery and/or transplant) had on parental perceptions about the illness, caregiving burden and quality of life. We expected the child’s treatment status to influence not only parents’ perceptions about the illness, but also the nature and degree of caregiving demands. Parents of children undergoing cancer treatment procedures deal with greater stressors, compared to those whose children have finished treatment [63].

Parents may witness their child experiencing pain and unpleasant side-effects and lifestyle restrictions due to aggressive medical procedures. Additionally, they may also struggle with the uncertainty about the effectiveness of treatment. When a child is receiving treatment, medical, nursing and emotional care demands increase considerably. Understandably, parents wish to be at the hospital, accompanying their ill child. Parental attention is greatly focused on providing comfort to a child who is suffering. Furthermore, during the active treatment phase, parents struggle with different strategies to gain their child’s co-operation with aversive medical procedures (e.g., taking medicine, physical exams). At the same time, parents must maintain their other roles in the family and in the wider social arena, such as in the sphere of employment. In this context, it becomes particularly difficult to balance job demands with multiple family needs, including financial needs that can arise or increase due to taking prolonged leave or where one or both of the parents give up their job altogether. The combination of these strains can lead to exhaustion, increasing the levels of caregiving burden, which, in turn, may negatively impact quality of life [64].

Certain types of radiation and chemotherapy can damage the reproductive system of children in ways that cannot be known until the system reaches maturity. Even when a boy or girl reaches adolescence, it may not be immediately apparent whether his or her reproductive system has suffered significant damage. It is often only when these survivors try to reproduce that these losses become apparent [58].

The possibility that cancer treatment might prevent a survivor from one day parenting children is very stressful. Fritz and Williams' sample reported a significant level of distress with regard to the possibility of sterility caused by cancer treatment. These cancer survivors perceived themselves as less attractive to others because of an uncertainty about their ability to reproduce, something most people their age are able to take for granted. The possibility of sterility causes considerable disruption in the normal courtship process for many cancer survivors. Pediatric cancer survivors in the this study reported an almost universal discomfort about discussing their cancer experience with the opposite sex [65].

2.8 Cognitive changes

In spite of the improvements in chemotherapy and radiation treatment, both can cause significant damage to the brain. This damage is often not apparent until later in life. The brain isnot fully developed until sometime late in adolescence. The introduction of radiation or chemicals that kill cells can impair brain development [58].

2.9 Risk of cognitive

Survivors of childhood cancer frequently experience cancer-related cognitive dysfunction, commonly months to years after treatment for pediatric brain tumors, acute lymphoblastic leukemia (ALL), or tumors involving the head and neck. Risk factors for cancer-related cognitive dysfunction include young age at diagnosis, treatment with cranial irradiation, use of parenteral or intrathecal methotrexate, female sex, and pre-existing comorbidities.

> Researchers mentioned that impairment varies with the type of treatment, the age of the child at the time of treatment, and the vulnerability of the particular brain systems or structures that are developing at the time of treatment [58].

Studies have demonstrated that specific types of treatments place the patient at risk for later cognitive deficits. Several studies reported learning difficulties related to cancer treatment [11,66]. For this sample, the treatment for pediatric Hodgkin's disease did not cause significant cognitive impairment Copeland and his colleagues [67].

2.10 Parent Stressors

The experience of pediatric cancer seriously disrupts normal family life. As primary caretakers and providers, parents experience a great deal of stress living with a child who has cancer. The demands of medical care produce a variety of stressors.

Parents experience interpersonal, intellectual, financial, and existential stress from the demands of securing medical care for their ill child. Additionally, the uncertainty of their child's future is a significant cause of stress for these parents. Parent stress related to diagnosis and treatment of cancer is well documented. Parents in this study identified many different activities that were very stressful.

As might be predicted, hospital admissions were identified as being extremely stressful for these parents. One of the most stressful parts of hospital admissions was also identified as causing stress across all aspects of securing treatment: waiting. Waiting for the doctor during outpatient visits, waiting for a fasting child to be able to eat, waiting for their child to be discharged from the hospital, waiting for test results, waiting while the child receives treatment, and waiting to hear the outcome of a medical procedure were all stressful for parents [68].

Having a child with cancer also creates a strain on family finances found that the cost of travel, hotels, meals, and loss of income suffered by their sample was a considerable stressor. Additionally, these authors reported that the lowest paid workers are typically most likely to lose income for taking time off from work. Klassen and his colleagues reported that it is not uncommon for parents of pediatric cancer patients who take off a great deal of time to lose their jobs. When this occurs, it puts a tremendous stress on parents and the entire family.

Family members' reactions to the cancer were reported to cause stress for parents. Researchers reported that parents experienced negative reactions regarding the cancer experience from both the patient and his or her healthy siblings. Parents' reported that a certain amount of negativity was expected and that they were able to cope fairly well with the expected reactions. However, extreme reactions from either the cancer patients or their siblings caused considerable stress for the parents [69].

2.11 Sibling Stressors

For healthy siblings, having a brother or sister with cancer is a tremendously traumatic situation. Cairns and her colleagues (2010) discovered that siblings of childhood cancer patients were often more distressed than the afflicted family member about the disease. These researchers discovered that having an unwell brother or sister made healthy children worry about their own health. Other researchers have found that siblings had a worse psychological adjustment than the sick themselves [70,71].

2.12 Sleep effects

Sleep is a fundamental biological process necessary for the development and maintenance of physical and psychological health. Good sleep quality plays a vital role in metabolic and hormonal regulation [72] as well as learning and memory consolidation [73]. In contrast, shorter sleep duration in children and adolescents has been associated with impaired school functioning [74], obesity [75,76], cardiovascular disease [77], and depression and anxiety [78].

Children and adolescents who are diagnosed with pediatric cancers are at risk for experiencing these negative outcomes as part of their disease and treatment, and are at risk for experiencing disturbed sleep.Children and adolescents who are diagnosed with pediatric cancers are at risk for experiencing these negative outcomes as part of their disease and treatment, and are at risk for experiencing disturbed sleep. Thus, sleep may be a partial mediator of the psychological and physical consequences of a pediatric cancer diagnosis. The Behavioral Model of Insomnia is widely used to explain the process by which acute instances of disrupted sleep become chronic and persistent [79].

In this model, predisposing factors (e.g. individual trait characteristics) interact with precipitating factors (e.g. sudden physical illness and/or changes to the sleep environment), which triggers an acute episode of insomnia. Subsequently, perpetuating factors and conditioned arousal develop and maintain chronic insomnia. Perpetuating factors are maladaptive strategies that individuals use to fix his/her transient sleeping schedules. These strategies can refer to the individual spending an excessive amount of time in bed by going to bed earlier, getting out of bed later, and taking frequent naps. Perpetuating factors can create irregular sleep schedules, which are commonly seen in the pediatric cancer population because of nighttime awakenings for medical monitoring or from treatment side effects, and can further disturb circadian rhythms [80].

For example, as the individual spends more time in bed in a wakened/aroused state, they associate wakefulness and arousal with cues that are normally associated with sleep (i.e. being in bed). Conditioned arousal can lead tomaintenance of sleep disturbances even in the absence of the original precipitating factors. Similar mechanisms may contribute to the development of chronically disturbed sleep within the pediatric cancer survivor population. It has been estimated that 30% to 50% of newly diagnosed or recently treated adult cancer patients experience sleep disruptions, nearly twice as high as in the general population [81].

Additionally, when compared to sibling controls, adult survivors of childhood cancer report significantly more disrupted sleep and excessive daytime sleepiness [82]. Analogous to adult populations of cancer patients, pediatric cancer patients also report sleep difficulties, especially in initiating and maintaining their sleep [83,84].

Sleep disturbances in the pediatric population are further characterized by decreased quality of life [85] and exacerbated neurocognitive difficulties in survivorship[86].

CHAPTER THREE

METHODOLOGY

3.1Design of the study

A descriptive cross-sectional study was conducted to assess the nature of the life of caring families for a child with cancer in Basra Specialized Hospital for Cancer Diseases, and this study began in December 2021 .

3.2sample of study

The current study included a group of families in Basra governorate from separate areas in the governorate, which included 30 families with varying degrees of kinship with the patient from the father, mother, brother, sister, grandmother, grandfather, and aunt or uncle.

3.3Project instrument

A project questionnaire tool that was prepared according to scientific sources related to the subject of the research and approved by specialized professors. The questionnaire was selected from (2) of the parts. The first part contained (14), which included variables (the age of the accompanying patient, the degree of kinship, the patient's age, gender, and the economic status of the families).

The second part contained (34) to assess the nature of the life of the caring families of a child with cancer. The questions were separated into positive and negative questions. The positive questions about them received yes to a full degree, and those favored by them got B to a lower degree, while the opposite is true for the negative. All participants answered two parts of the questions. Through the direct interview, we collected the result according to the correct model answer

3.4Methods of work

1. Distribution of questionnaires to accompanying patients inside the hospital
2. Conducting an interview with each facility to collect accurate data on the subject
3. Collecting the results of the questionnaire and tabulating them in Excel tables .
4. Statistical analysis of the classified results in the SPSS program version 26 to extract the significant values of the study samples and the accuracy rate is 0.05.
5. Discussing the results of the questionnaire and statistical analysis

CHAPTER FOUR

RESULTS AND DISCUSSION

The studying and understanding of psychological, physical ,and social effects in the families of children with cancer is considered as effective empowerment of family members to address the obstacles and pressures they face . The ability of parents to find adaptive strategies during a child's therapy is important to their mental and physical health as well as their children's well-being and the long-term adaptation of disease.

1. Rating and scoring of the study of questionnaire

A three-point Likert scale was used statistically to evaluate the questionnaire as harmful ,healthy, or acceptable to the study samples ,families and their children with cancer.Thus, the harmful factors are in the range (1-1.66),the acceptable factors in the range (1.67-2.33), and the health factors in the range (2.34-3) as shown in table (4.1).

Table 4. 1 three points Likert Scale for questionnaire evaluation

Likert Scale	Interval	ifference	Evaluation
1	1 – 1.66	0.66	**Harmful**
2	1.67 – 2.33	0.66	**Acceptable**
3	2.34 – 3	0.66	**Healthy**

2. Sample Characteristics

Table (4.2) shows that of the 30 families involved, 24(80%) patient facilities were mothers and 6(20%) relatives, the almost of whom was 13(43.3%) between the ages of 30-39, and the sickest children were the same number as 15(50%) among males and females,8(26.7%) were aged 1-6 years and 10(33.3%) were aged 7-11 years and 12(40%) respectively were 12-16 years old. The weight of must sick children (50%)ranged from 20-30 kg, while 5(16.7%) were with high weight 60-70 kg.

According to the educational level of the, 18(60%) received a secondary school, 5(16.7%) received high school ,4(13.3%) an institute,and 3(10%) were college graduates. The economic status of the families was 13(43.3%) families with average income, 9(30%) families with low incomes and 8(26.7%) families with good incomes.Of the 30 families , 14(46.7%)had a history of cancer versus, 16(53.3%)had no history of disease. Finally, the percentage was similar to that of the mother or father,26(86.7%) of the mothers were in good health and 27(90%) of the fathers were in good health.

Table 4. 2 General demographic characteristics of participant families and their child patients.

descriptive statistics of Demographic Variables			
mographic Variables	**riables Classes**	**F**	**Percent**
Patient's relatives	Mother	24	**80.0**
	Relatives	6	**20.0**
	Total	30	**100 %**
Age of kin	20 – 29	8	**26.7**
	30 – 39	13	**43.3**
	40 – 49	4	**13.3**
	More than 50	5	**16.7**
	Total	30	**100 %**
Patient's age	1 – 6	8	**26.7**
	7 – 11	10	**33.3**
	12 – 16	12	**40.0**
	Total	30	**100 %**
Patient's sex	Male	15	**50.0**
	Female	15	**50.0**
	Total	30	**100.0**
Patient's weight	20 – 30	15	**50.0**
	30 – 40	3	**10.0**
	50 – 60	7	**23.3**
	60 – 70	5	**16.7**
	Total	30	**100 %**
Education level	Secondary school	18	**60.0**
	High school	5	**16.7**
	Institute	4	**13.3**
	College	3	**10.0**
	Total	30	**100 %**
Address	City center	17	**56.7**
	Out center	13	**43.3**
	Total	30	**100.0**
	Poor	9	**30.0**

Economic status	Medium	13	**43.3**
	Good	8	**26.7**
	Total	30	**100.0**
House	Estate	17	**56.7**
	Rent	8	**26.7**
	Slums	5	**16.7**
	Total	30	**100.0**
Cancer History in Family	Yes	14	**46.7**
	No	16	**53.3**
	Total	30	**100.0**
health condition of mother	Yes	26	**86.7**
	No	4	**13.3**
	Total	30	**100.0**
health condition of father	Yes	27	**90.0**
	No	3	**10.0**
	Total	30	**100.0**

3. Questionnaire Item Analysis

Each section of the questionnaire items was evaluated to determine their strength and moral impact on psychological and emotional stress of families and their sick children. As shown in table (4-3), the analysis was conducted on all the collected data to determine whether they were harmful, healthy or acceptable.

According to the table above, the elements of healthy questions were seven and they have (2.34-3) mean score on three-points Likert scale, this indicates that these factors do not affect stress in families and their children. The questionnaire elements of acceptable stress effect were 15 and have (1.67-2.33) mean score on Likert scale. Finally, the questionnaire elements of harmful stress effect were 12 with mean score of (1-1.66)on Likert scale.

The items of the questions in the table above can be summarized and rearranged into a group of factors that differently affecting the state of family stress, table (4-4).

From this table it is understood that the state of adaptation was present in families and children for most of the questions that pertain to this factor, except in the event of the death of a child in a hospital or an obsession with the fear of a return of the disease after recovery, as well as spending long periods in the hospital. For community and family members, the results were acceptable, as the disease did not change the relationship with them. The economic factor was harmful causing a pressure with psychological stress on most families, especially the poor and middle income ones.

Table 4. 3Mean score and assessment for each questions about Lifestyle of Patient's family

Question No.	N	Min	Max	Mean score	Sd	Ass.
Q1	30	1	3	1.93	0.907	Acceptable
Q2	30	1	3	1.87	0.937	Acceptable
Q3	30	1	3	2.67	0.606	Healthy
Q4	30	1	1	1.00	0.000	Harmful
Q5	30	1	3	1.23	0.568	Harmful
Q6	30	1	3	2.17	0.834	Acceptable
Q7	30	1	3	2.47	0.819	Acceptable
Q8	30	1	3	2.63	0.615	Healthy
Q9	30	1	3	2.83	0.531	Healthy
Q10	30	1	3	1.63	0.850	Harmful
Q11	30	1	3	1.80	0.887	Acceptable
Q12	30	1	3	1.87	0.937	Acceptable
Q13	30	1	3	1.97	0.999	Acceptable
Q14	30	1	3	2.77	0.626	Harmful
Q15	30	1	3	1.27	0.691	Harmful
Q16	30	1	3	1.13	0.434	Harmful
Q17	30	1	3	1.53	0.571	Harmful
Q18	30	1	3	1.40	0.814	Harmful
Q19	30	1	3	2.10	0.960	Acceptable
Q20	30	1	3	2.20	0.997	Acceptable
Q21	30	1	3	1.50	0.820	Harmful
Q22	30	1	3	1.40	0.770	Harmful
Q23	30	1	3	2.27	0.740	Acceptable
Q24	30	1	3	2.57	0.774	Healthy

Q25	30	1	3	1.93	0.828	Acceptable
Q26	30	1	3	1.60	0.932	Harmful
Q27	30	1	3	2.33	0.884	Acceptable
Q28	30	1	3	2.50	0.572	Healthy
Q29	30	1	3	1.70	0.750	Acceptable
Q30	30	1	3	2.37	0.809	Healthy
Q31	30	1	3	1.50	0.820	Harmful
Q32	30	1	3	1.87	0.937	Acceptable
Q33	30	1	3	2.03	0.809	Acceptable
Q34	30	1	3	1.63	0.928	Harmful

***Harmful = (1-1.66),Acceptable = (1.67 – 2.33), Healthy = (2.34 – 3)**

The community and moral support factors were available and acceptable to families, and the only exception that put them under psychological stress was the lack of a full recovery in hospital for a child to mentally enhanced other sick children, and that might be because cancer is one of the most difficult chronic disease and its treatments in our hospitals is limited to painkillers only. Educational stimulation is also a harmful psychological effort for children and their families, as most children become bored or leave school due to disease.

Table 4. 4The evaluation of effective factors of questionnaire

Factors	Question No.	valuation
Factor 1: coping with disease conditions	1,2,3,8,9,11,12,13,1617,23,27,32,33	Acceptable
	4,5,10	Harmful
Factor 2: Changing relationships with community or family members	6,25	Acceptable

Factor 3: Economic support	15,24, 26,28,34	Harmful
Factor 4: Social and moral support	7,19,20,23,25,29	Acceptable
	18	Harmful
Factor 6: Study effect	21,22	Harmful
Factor 6: Health effect	24,28,30	Healthy
	14,15,16,17,31	Harmful

Finally, the health factor was the same in terms of both positive and negative effects. While drugs and some medical tests are available, there is a harmful effects in terms of lack of psychiatrists for patients, a psychological reactions occur to the child, the failure to respond to psychiatric treatment or the inability of accompanyingperson to deal with patient emotion. Also, if they have to buy drugs or do some tests out of hospital which increases the money burden on the family.

In general, for the family lifestyle of the sick children under the present study, the table (4-5) shows the highest percentage of families (90%) were given an acceptable assessment of how to deal with and adapt to the stressful conditions due to their children ill, while (3%) of the families had a healthy assessment that was not affected by the psychological condition and stresses. On other hand, (7%) of the families were under a harmful and difficult psychological condition in their lifestyle, being families with a low and limited income.

Table 4. 5Levels of Overall assessment about Lifestyle of Patient families

Mean Score	Frequency	Percent	Assessment
0 – 0.33	2	7 %	Harmful
0.34 – 0.67	27	90 %	Acceptable
0.68 - 1	1	3 %	Healthy
Total	30	100 %	

Conclusions

1. There is a state of adaptation to the conditions of the disease for most families caring for a child with cancer.
2. The child's cancer did not affect the relations with community or between family members.
3. Most families were obsessed with the fear that the child would return to disease after recovery and from long periods of hospitalization.
4. Existence of physical, financial harm and psychological stress on middle-income or poor families.
5. There are little community and moral support for families.
6. The academic factor was negatively affected, as most of the children had their studies affected or stopped due to disease.
7. Damage in the health aspect due to the occurrence of psychological emotions of the child and there is no psychologists provided to follow up on this case.
8. A negative health impact on families due to the unavailability of some medical tests and treatments ,so they have to do it outside the hospital.

Recommendations

1. Intensifying the efforts of financial support organizations for middle-income or poor families with cancer children.
2. Providing means of communication to allow the cancer child to complete his studies, such as electronic lectures inside the hospital.
3. Reducing the financial pressure on families inside hospitals by providing more treatments or examinations so that the family does not have to conduct them outside the hospital.
4. Increasing attention to the patient child inside the hospital in terms of nutrition by providing the necessary and healthy food for them.

5.Equippnig hospitals with medical and nursing staff in psychology to help sick children and their families overcome emotional and stressful situations.

6. Educate the family caring for a cancer child about the need to consult a psychiatrist and to comply with his advice in order to avoid the child's emotional impact on the family.

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Appendices

الخبراء الذين تم عرض الاستبيان عليهم

قائمة الخبراء

	اسم الخبير	الشهادة	مكان العمل
1	أ .د محفوظ فلاح حسن	دكتوراه	كلية التمريض
2	أ.د.سجاد سالم عيسى	دكتوراه	كلية التمريض
3	أ.م.د.وصفي ظاهر عبد علي	دكتوراه	كلية التمريض
4	أ.م هاجر سالم عيسى	ماجستير	كلية التمريض
5	م .افكار فاضل	ماجستير	كلية التمريض
6	م .دعاء محمد باجي	ماجستير	كلية التمريض

استبيان تقييم نمط حياة الاسرة التي تحتضن طفل مصاب بالسرطان

عمر مرافق المريض 20- 29 ☐ 30-39 ☐ 40-49 ☐ اكثر من50 ☐

صلة الرابة من المريض الاب ☐ الام ☐ اجد او الجدة ☐ العم او العمة ☐ الخال او الخالة ☐ .

عمر الطفل المريض 5_6 سنوات ☐ 7 _ 11 ☐ 12- 16 ☐

الجنس ذكر ☐ انثى ☐

وزن الطفل 20-30كغم ☐ 30-40 ☐ 40-50 ☐ 60- ☐ 70

التحصيل الدراسي متوسطة ☐ اعدادية ☐ دبلوم ☐ كلية ☐

العنوان____________________ ريف ☐ قضاء مركز ☐ ☐

الحالة الاقتصادية ☐ جيد ضعيف ☐ متوسط ☐

نوع السكن ☐ ايجار ملك ☐ عشوائيات ☐

التشخيص) نوع السرطان(للمرض المدة الزمنية ☐ كلا ☐

هل توجد إصابة سابقة بالسرطان ضمن العائلة او الاقارب ☐ نعم ☐ ☐ العائلة ☐ العدد ☐ متوفية ☐

عدد حالات السرطان ضمن العائلة الواحدة ☐ يوجد ☐ لا يوجد

الحالة الصحية للأم سليمة مريضة

الحالة الصحية للأب ☐ سليم مريض متوفي

ت		نعم	كلا	الى حد ما
1	هل لديك قابلية التحمل لرؤية طفلك وهم يجرون له بعض الفحوصات المختبرية والعلاجات؟			
2	هل تحتاج للمساعدة عند رعاية طفلك؟			
3	هل تستطيع العائلة التعامل مع الآثار الجانبية للمرض ؟			
4	هل تشعر بالتأثير النفسي السلبي (حزن شديد) عليك او على طفلك عند حدوث حالة وفاة لمريض اخر مشابه لمرض طفلك؟			
5	هل تشعر بهاجس الخوف من احتمال عودة المرض لطفلك بعد العلاج والتحسن ؟			
6	هل ترى ان مرض طفلك له اثر سلبي على علاقة افراد الاسرة مع بعضهم البعض؟			
7	هل تحصل العائلة على دعم عاطفي من الأقارب والأصدقاء؟			
8	هل اثر مرض طفلك سلبا على المستوى الدراسي لإخوانه؟			
9	هل هنالك تعاون بين الزوجين لرعاية طفلهم؟			
10	هل تقضون فترة طويلة في المستشفى؟			
11	هل تتجاوز فترة الرقود في المستشفى (الشهر)؟			
12	هل تعاني من اضطرابات في النوم؟			
13	هل اضطررت لأخذ بعض الادوية المسكنة بعد إصابة طفلك بالمرض؟			
14	هل هنالك طبيب نفسي في المستشفى يتابع حالة الأطفال وعوائلهم؟			
15	في حالة وجود الطبيب النفسي هل هنالك أستفاده من نصائحه لحل بعض المشاكل النفسية؟			
16	هل تحدث لطفلك مشاكل نفسية؟			
17	هل لديك القدرة للتعامل مع النوبات العصبية والنفسية التي تحدث لطفلك؟			
18	هل لديك احد اقاربك او اصدقائك او احد معارفك لديه طفل مريض بالسرطان وشوفي من مرضه؟			
19	هل تعتقد ان طفلك سوف لن ينجو من المرض؟			
20	هل طفلك طالب في المدرسة؟			
21	هل لايزال مستمر بدراسته؟			
22	هل اثر مرضه على مستواه الدراسي؟			
23	هل المرض في تحسن الان؟			
24	هل يحتاج الطفل اثناء العلاج لتواجد المرافق مع الكادر الطبي؟			

25	هل يؤثر وجود طفل مصاب بالسرطان على التواصل الاجتماعي بينالعائلة المحتضنة وبقية المجتمع ؟			
26	هل تعتمد الاسرة على مصدر دخل اخر او بالتعاون مع افراد الاسرة الاخرين؟			
27	هل تم فقدان الوظيفة او العمل لاحد الوالدين بعد تشخيص المرض؟			
28	هل الادوية متوفرة بصورة كافية داخل المستشفى ؟			
29	هل تجد العائلة اي استجابة من العلاجات المعطاة للمريض او مجرد تسكين للألم ؟			
30	هل تتوفر جميع الفحوصات المختبرية في المستشفى؟			
31	في حالة عدم توفر بعضها هل تضطر لأجراء تلك الفحوصات خارج المستشفى على نفقتك الخاصة؟			
32	هل يشكل بعد السكن عائق لتلبية احتياجاتك واحتياجات طفلك طول فترة رقوده في المستشفى؟			
33	هل يتوفر الغذاء المناسب لطفلك في المستشفى؟			
34	هل تضطر لشراء وجبات الغذاء من خارج المستشفى؟			

الخلاصة

تضمنت الدراسة الحالية تقييم تأثير وارتباط الضغوطات النفسية والمادية والاجتماعية والمعنوية لدى الاطفال المصابين بالسرطان وعائلاتهم المراعين لهم .بدأت الدراسة بتاريخ 2021/12/1 اذ تم اخذ عينات من 30 عائلة ممن لديهم اطفال مصابين بالسرطان يرقدون في مستشفى الطفل التخصصي للأمراض السرطانية في محافظة البصرة , حيث وزعت عليهم اوراق أسئلة أستبيانية تدور حول الاجهاد النفسي والمادي والمجتمعي ونمط الحياة عندهم .بينت النتائج ان معظم المرافقين للطفل المريض هم من الامهات والاشقاء او الاقرباء بينما كان دور الاباء اقل بسبب انشغالات العمل والمعيشة , وان 90% من العائلات كانت لديهم حالة تكيف نفسي مع وجود المرض في طفلهم ولم يؤثر ذلك على تغيير العلاقات مع المجتمع او بين افراد الاسرة الواحدة. كان العامل الصحي والعلاجي متباينا في التأثير فهو كان سلبيا من حيث عدم توفر اطباء نفسيين وعدم توفر بعض الادوية والفحوصات وأيضا كان ضارا وسلبيا من جانب حدوث الانفعالات النفسية للمريض وعدم الاستجابة للعلاج وكذلك الاضطرار لأجراء بعض الفحوصات وشراء الادوية الغالية الثمن من خارج المستشفى . كذلك وفي الاغلب كان العامل الاقتصادي ضارا بشكل مؤثر ومسببا للأجهاد على العائلات , وخاصة ضعيفة الدخل منها ,الى جانب فترات الرقود الطويلة في المستشفى واقتصار العلاجات على مسكنات الالم مما ادى لفقدان وتلكؤ معظم الاطفال المرضى لفرص اكمال دراستهم .

الاستنتاجات: أن العوامل المادية والصحية من ناحية فترات العلاج الطويلة مع الصرف المادي المتزايد دون استجابة اضافة فقدان المستقبل الدراسي والتعليمي هي اكثر الضغوط والاجهادات النفسية التي يعاني منها الاطفال مع عائلاتهم.

التوصيات:

توفير الدعم المادي والصحي للمرضى في المستشفيات من كادر طبي وتمريضي لمتابعة وتخفيف الضغوط النفسية للمرضى وذويهم وكذلك محاولة ايصال التعليم اليهم الكترونيا بدلا من فقدان مستقبلهم الدراسي او تكبدهم عناء الذهاب للمدارس وهم يعانون المرض.

University of basrah
College of Nursing
Basic medical sciences

تقييم العوامل الاجتماعية الديموغرافية والضغط النفسي والمادي لدى عائلات الاطفال المصابين بالسرطان في العراق

مشروع بحث مقدم الى مجلس كلية التمريض جامعة البصرة كجزء من متطلبات نيل درجة بكالوريوس في علوم التمريض

من قبل الطالبتين

حميدة عكاب حمود

نرجس علاء

المرحلة الرابعة

المشرف

م.د عبدالمطلب عبدالله محمد

2021-2022