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Research Article

Psychosocial Impact of Childhood Cancer on Patients and their Families

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ABSTRACT

Background: The presence of cancer has a deep psychological impact on the quality of life of patients, on family and social relationships.

Aims: To assess the impact of childhood cancer on patients and their families.

Subjects and methods: A Prospective questionnaire-based study, for 151 patients, had malignancy identified by tumor registry of Children Welfare Teaching Hospital conducted in the period from January till December 2015. The information were taken from the parent(s) in the presence of the patient who sometimes answered some questions during the interview.

Results: There was an interview with 151 families of children with malignant diseases in the outpatient clinic. Sixty-two (41%) patients have leukemia while 89 (59%) have solid tumors. Boys (64.2%) were more than girls (35.8). Regarding patients at time of interview, the mean age was 10.2 years, while at diagnosis it was 7.1 years. The majority of the parents accepted the diagnosis (89.4%), the rest of the parents (10.6%) were skeptical and tried to re-evaluate the condition elsewhere. More than one-half of the parents started to have quick temper (54%) after diagnosis. Most of them had sleep difficulties (83.2%) after diagnosis. Neglection of other siblings in the family was reported in more than one-half of the interviewed families (52.1%). Most of the parents lost their emotional control (69.2%) with the surrounding people after knowing the diagnosis. After an initial period of treatment, there was a decrease in the social activity of the families in 42% of cases. There was a high concern of the parents about the patient's future marriage (69%), conception (62%), and career (52%).

Conclusions: The establishment of a multidisciplinary cancer care team including social workers, teachers, psychologists, and others to support the child and family is seems to be mandatory during the whole period of treatment and thereafter.

Introduction

The diagnosis of pediatric cancer represents a scarring, mind-blowing, and traumatic tragedy for the family. Once diagnosed, it starts putting a deep psychological effect on the quality of life of children and their parents, extending to the social connections, and on role functioning. These effects are further affected negatively by treatment, which engorged the intellectual and emotional energy of affected children and their parents and leads to effects that further restrain role functioning and quality of life. With regard to the financial impact, the mere diagnosis of cancer constringes the possibility for being suitable for a future paid work (employment), and therapy and its short- or long-term effects spoil personal and family wealth and reduce fertility (1)

A previous story with cancer might lead to immediate anticipation that the sick patient will die. Even if the disease is not deadly to an extent, ideas about a long, harmful and unpleasant treatment course may be pulverizing. The way in which the diagnosis of cancer is settled significantly affects the family's initial response and shape the level for cooperation with the health care team (2).

Since 1960s, advances in treatment techniques, as well as supportive care, have created dramatic improvements in the survival of pediatric cancers.

As a result, in this early part of the 21st century, pediatric oncology treatment goes beyond seeking cures to include a focus on the short and long-term quality of life of the child or adolescent patient, their siblings, and parents. Successful developmental and psychosocial outcomes for the patient and family hinge on thoughtful assessment, dedication to prevention of physical, neurocognitive and psychosocial late effects, and well-orchestrated collaboration by a multidisciplinary health care team (3)

Iraqi people are compassionate and strongly entangled with their extended family and their tribe, which provide both psychological, social and spiritual support to the child and his family, in addition to the financial and moral support (4).

The concepts presented by the current study try to provide a systematic scope for working with children and families facing the diagnosis of cancer during childhood. The aim was to evaluate the impact of childhood cancer on patients and their families.

Subjects and methods:

The study design is Prospective and questionnaire-based, for 151 patients were diagnosed in Hemato-oncology department, Children Welfare Hospital, Medical City, Baghdad during the period January 1st till December 31st 2015. In the survey a questionnaire was used for the collection of information including patient and family demography, type of tumor, parent's education, income, size of family, age of child at diagnosis, family support, behavior problem in the child and family, etc. Not all parameters included all targeted index persons; this is due to either absence of index person at time of interview or non-applicable questionnaire or refusal to answer the question.

The information were taken from the parent(s) with the presence of the patients who sometimes answered some questions during the interview. In 119 (78.8%) interviews, the discussion was with one of the parents, while 24 (15.9%) interviews with both parents and 8 (5.3%) interviews done with patients alone.

Ethical approval

Ethical approval was obtained from the local committee at Children Welfare Teaching Hospital and from participants. The legal guardians of eligible patients were approached and invited to participate in this study. In accordance with the Helsinki Declaration of ethical principles, informed verbal consent was obtained from the legal guardians before enrolment in this study. (5)

Descriptive analysis

This was performed to describe the study sample using frequencies for categorical variables and mean and median for continuous variables. All analyses were performed using IBM SPSS statistics (SPSS, Chicago, IL, USA) for mac, version 20.0. (6)

Results

Interviewed sample

There was an interview with 151 families of children with cancer in the outpatient clinic in addition to inpatient ward of Children Welfare Teaching Hospital. Sixty-two (41%) patients have leukemia while 89 (59%) have solid tumors. Boys were more than girls, (97 male (64.2%) vs 54 female (35.8%) respectively). Large family size (> 5 members) was reported in 52 (34.4%) families, 58% of families reside in Baghdad, the rest in other governorates of Iraq.

Regarding patients, the mean age at time of interview was 10.2 year, while the mean age at time of diagnosis was 7.1 years. There were 63 patients below 10 years of age. Parent's age was taken during the interview; father's median age was older than mothers.

In 119 (78.8%) interviews, the discussion was with one of the parents, in 24 (15.9%) with both parents and 8 (5.3%) interviews done with patients alone.

Table 1: Descriptive feature of the 151 patients

Item	Description	No.	%	
Diagnosis	Leukemia	62	41	
	Solid tumors	89	59	
Gender	Male	97	64.2	
	Female	54	35.8	
Age group	<10	63	41.7	
	>10	88	58.3	
Family size	<5	99	65.56	
	>5	52	34.43	
	No.	**Mean**	**Range**	**Median**	**SD**
Age at interview	151	10.2	2-19	11	4.3
Age at diagnosis	151	7.1	0.4 -15	7	3.7
Age of father	147	43.3	21-68	43	8.2
Age of mother	143	38.8	22-60	39	7.3

Descriptive information of parents

One half of the fathers of interviewed patients were wage earner (50.7%), while most of the mothers (about 86%) were house wives.

Fathers who finished secondary school & higher education were slightly higher than mothers (58% & 44% respectively).

Table 2: Job and Education of parents

Item	Description	Father	Mother
		No. (%)	**No. (%)**
Job	Not employee	10(7)	128(85.9)
	Earner	73(50,7)	2(1.4)
	Employee	61(42.3)	19(12.7)
	Total	144 (100)	149 (100)
Education	Illiterate	16(10.6)	29(19.2)
	Read & write only	6(4)	9(6)
	Primary school	42(27.8)	47(31.1)
	Secondary school	47(31.1)	42(27.8)
	Higher education	40(26.5)	24(15.9)
	Total	151 (100)	151 (100)

Parents' responses after diagnosis

The majority of the parents accepted the diagnosis (89.4%) either in our hospital or as they were referred from other hospitals or health professionals, the rest of parents (10.6%) were skeptic and tried to re-evaluate the condition elsewhere.

Less than one quarter of the parents (20.4%) had conflict about the treatment decision, the rest of parents accepted all the management plan or policy in the oncology unit.

Most of the family refused to use herbal (or folk) medicine for their child (90%) as an adjuvant tool of the treatment, they were convinced with treatment policy of the oncology unit. More than half of parents, either single or both have the sense of guilt.

Table 3: Action of the parents

Item	Description	No. (%)
Acceptance the diagnosis	Accepted	127(89.4)
	Not accepted	15(10.6)
	Total	142 (100)
Conflict about treatment	Yes	29 (20.4)
	No	113 (79.5)
	Total	142 (100)
Herbals/Folk medicine with therapy	No	129(90.2)
	Yes	14(9.8)
	Total	143 (100)
Sense of guilt	No	61(43.2)
	Both	44(31.2)
	Father	18(12.7)
	Mother	18(12.7)
	Total	141

Parental problems during the illness

More than one half of the parents started to have quick temper (54%) after diagnosis, they deny any previous similar reaction before their children's illnesses. Most of them had sleep difficulties (83.2%) after diagnosis. Neglection of other siblings in the family was reported in more than one half of the interviewed families (52.1%).

About three quarter of the parents worried about hair loss of their children (72.3%) after knowing the side effects of chemotherapy since early days after diagnosis. Most of the parents lost their emotional control (69.2%) with the surrounding people after knowing the diagnosis.

In 39/135 (28.8%) interviewed families; there was a disturbed social relation between the parents.

There was a change in patient's behavior after diagnosis and during the phases of treatment, this was reflected by loss of patient's control inside home and hospital in 35%, Children who started to abuse their parents physically and verbally was reported in 55% of families. After initial period of treatment, there was a decrease in social activity of the families in 42% of cases.

In 17% of families, there was a decision to stop future pregnancies because there was a concern about having another child with cancer.

There was high concern of the parents about the patient's future marriage (69%), conception (62%) and career (52%).

Table 4: Parental problems

Item	Positive/ total *	%
Quick tempter	77/143	53.8
Parental sleep difficulties after diagnosis	119/143	83.2
Neglecting other children in the family	72/138	52.1
Concern about hair loss of patients	103/142	72.3
Loss of parent's emotional control at diagnosis	99/143	69.2
Disturbed relation between parents	39/135	28.8
Decreased social activity of the family	60/143	41.9
Plan to stop future pregnancy	23/133	17.2
Worry about patient's future career	74/143	51.7
Worry about patient's future marriage	99/143	69.2
Worry about patient's future fertility problem	89/143	62.3
Loss of patient control	47/135	34.8
Presence of verbal or physical abuse by patient	70/127	55.1

*Total number represents the answer of the patients toward each question.

Patients' and sibling' problems during the period of treatment:

Reviewing patient's answers on certain questions, the cohort shows half of the patients had feeling that they were more mature than their peers, 72% had psychological problem from hair loss, 62% of them had fear from recurrence of disease and 53% had fear from death and 23% of patients got disturbed relation with peers. On the other hand; one or more siblings express jealousy feeling toward the patient in 59% of families, school performance was affected in 38% of siblings and in 15% of families, siblings had school interruptions.

Table 5: Patients' and sibling' problems

Problem	Positive/total *	%
Patient's problems		
Feeling more mature than peers	38/76	50
Psychological problem from hair loss	55/76	72
Fear from recurrence of disease	41/66	62.1
Fear from death	36/67	53.7
Disturb relation with peers	20/86	23.2
Sibling's problems		
Jealous feeling of sibling toward the patient	80/135	59.2
Decreased school performance of the sibling	47/123	38.2
School interruption of siblings	19/123	15.4

*Total number represents the answer of the patients toward each question

Discussion

Mental health was notified and acknowledged earlier as an essential sector of people's general health. "Psychiatric hospital care in Iraq began as early as the late eighth century with Islamic hospitals, which incorporated Galenic medicine, spirituality, mysticism and music therapies in treating persons with mental illness". (7)

Currently, the information available about the burden of cancer diagnosis on the emotional, social and economic aspects of life of family of children with newly diagnosed cancer are limited in Iraq. Hence, here we tried to figure out the steps to evaluate the psychological, socioeconomic, and the coping methods related to pediatric cancer and the burden of the diagnosis on the pediatric patients and their families in Iraq. Selected children were having cancer diagnosis which had been made at least 6 months before enrollment into the current study.

The structure of the family in our culture, passed on from old times, represents a definite strength in the coping measures offered by the parents of the child with cancer. Our society is young with big family size and an extended family relation which has dual effects; it makes the parents have to consider other priorities beside their child's illness and at the same time it is the source of psychological support for the family in the early days or weeks of life.

There was both spiritual and psychological assistance from the grandparents. Shared care was also pros in this equation as other siblings were looked after by uncles, aunts and grandparents. This property is different from western societies where nuclear families predominate. The trauma of malignancy was expressed in the life of siblings on most of the families. The siblings exhibited fearful behavior with deteriorating school performance and ranking. The diagnosis of malignancy had an integrated effect on the family in most cases. The most outstanding feature was behavioral issues in the cancer children. (8)

In this study; having parent's age around 40 years, with a median age of patient of 7 years at time of diagnosis, one third of patients have big size family, with leukemia forming about 40% of patients, this put some pressure on the family on three aspects; financial, physical and social. Having half of the fathers being wage earner increase the burden on the family as they will leave their daily wages and stay in the hospital during the stay of their children just to be present in case the patients need food or drugs or additional investigations, and having three quarters of mothers being housewives increase the burden on the family members who stayed at home especially with big family size. The estimated event-free survival for patients with acute lymphoblastic leukemia was low compared with the international standard rate; however, abandonment of treatment was one of the important factors against improving the survival rate. (9)

A child's malignant diagnosis represents a distressing and shocking fact for the families on all circumstances. In countries with limited resources and in post war periods, life has already many significant challenges, cancer diagnosis news will add further negative impact. Furthermore, they are stunned when they discover that medical equipment needed for diagnostic purposes and treatment are either not available or of questionable standards. (10)

Having quick temper, sleep difficulties, disturbed social relation of the parents and neglection of other family members at home might be a normal reaction after having the diagnosis in a family who live among an exhausted society like ours where the challenges are continuous. Deceased social activities of the family not necessary indicate that they became busy, indeed the cancer is considered a stigma in our society made the relatives and friends having some withdrawal from the family or there is concern of having an infection from other visitors.

Although the fact that hair loss is reversible and it is the least harmful side effects, still three quarters of families were worried about this issue even after having full explanation from the medical staff. Hair loss is a well-known flag that the patient has cancer and receiving chemotherapy, so the family is hesitant about disclosing information about their child's illness as it might affect their relationships with other family members and with other members of their community – teachers at school and neighbors at home.

Loss of patient's control was seen in one third and parent's abuse by the child was reported in about half of families and this might be expected in our settings, the parents don't want, or don't have a way (they don't know how) to talk with their sick child or with the other children about cancer. In addition, lack of palliative care service in Iraq made the story of treating cancer is a tragic painful one and the main player/victim is the patient.

The decision to stop future pregnancy in some families (17%) raised the degree of phobia from the disease, although there are continuous questions about the inheritance of the cancer and the reasonable explanation by the medical team, still there is concern about this issue.

As we are reproductive society; there is a major concern of any family about future fertility of their children and as the cancer with its treatment is strongly related to infertility, there were a recognized concern of the interviewed families from future marriage (69%), conception (62%) and career (52%).

Although the services are free, but many needs are missing and ultimately the cost is much higher than anyone would expect, whether for surgical interference or laboratory tests or medications or special visits to the private clinics before getting the diagnosis and even during therapy for follow up. These facts, in the background that 79% of families have modest monthly income, and in the majority of families either the father or the mother left work, this has a major negative impact on the way of living of the family that has a child with cancer. Furthermore, as most of diagnostic and therapeutic tools are offered at time of the working hours, this means that there is a potential for increased loss of income for the caregivers within the family leading to financial constraints. The increasing costs involved in the care for children with cancer comprised 3 major aspects: direct, indirect, and uncharted costs. Direct costs include the costs of medical services obtained and non-medical costs such as costs spent in the process of delivering the medical care, for example transportation and hotel stay. Indirect costs include loss of productivity associated with the illness like when a parent has to take leave to bring his child for therapy. Whilst the uncharted costs are, for example, costs of analgesics and other suffering related to cancer diagnosis and its treatment.

Iraqi culture views the child as having no right to decide things for him/herself or to do most things alone, this is reflected in having 50% of children either knew about the diagnosis after finishing treatment or even don’t know the diagnosis yet. Even though, half of those who knew the diagnosis, the parents were not the source, it might reflect a fact that the parents don't want to talk with their sick child or with the siblings about cancer.

Although we had answers from older children during the interview about being mature more than peers or having sense of fear from recurrence of disease or death, it might not be the right question or it should be better designed to have an objective answer. In the current study, the majority of patients’ parents were non-governmental employees (earners or non-employee at all). Current numbers indicate that unemployment is deeply embedded in Iraq, placing the country on an edge of abyss making serious challenges of the country’s educational status. (11)

In Iraq; there is no multidisciplinary team to help in delivering the holistic care to patients. There are no social or spiritual advisors who might improve the psychological state of the child or family, or nurture their spiritual strength, and no one who might distract them with meaningful activities.

We acknowledge that there are limitations of our study; this is a small sample size and it was a hospital-based study. The cross-sectional nature of the study further limits the findings and the benefits of longitudinal study should be considered and put into account especially for assessing the impact and coping mechanisms in these families. However, the strength of our study is that it is the first of its kind in children’s oncology unit in Iraq.

Conclusion

Malignant diseases have a major psychological impact on the child as well as his family. While the presence of extended family in our culture plays a positive role in supporting the parents throughout the duration of treatment, but loss or interruption in jobs for a significant period of time as most of the fathers are working on daily wages and this led to financial burden on the family.

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Conflict of Interest

No conflict of interest

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