THE SPECTRUM OF SOCIO-ECONOMIC BARRIERS OF FAMILIES OF CHILDREN WITH CANCER DURING CROSS-BORDER CARE: A PAEDIATRIC TERTIARY CARE HOSPITAL EXPERIENCE

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ABSTRACT

Background: Childhood cancer care needs timely access to diagnostic, treatment, and follow-up services for better survival of these children. Unfortunately, there is a lack of established comprehensive childhood cancer centers in Afghanistan, so these children with cancer and blood disorders consult healthcare providers working cross-border to seek specialized care. The research to explore the distress linked with childhood cancer and associated socioeconomic hurdles is lacking in low-middle-income LMIC countries. **Objective**: To evaluate the challenges faced by these families while their children with cancer are being managed cross-border in Pakistan. **Methodology**: This is a cross-sectional study done at Children's Hospital Lahore, Pakistan, from 1st January 2023 to 31st March 2023. The study involved families with twenty-four children. We interviewed the Afghan families of these children to understand the challenges they faced during this ordeal. **Results**: The study included children with a mean age of 7.4 years; only 21% were females. They spoke Pushto and Dari languages. Twenty-five percent did not understand Urdu, finding communication exceedingly difficult in 50% of families. Only 4 families had the facility of a translator. Sixty-seven percent were diagnosed with acute lymphoblastic leukemia, and the rest with solid malignancies. The monthly family income was meager. In 85% of cases, the remaining family was sponsored by loans or charity, and 75% were escorted by one or both parents. Ninety-five percent took loans and had a significant effect on siblings education and emotional well-being. Eighty-five percent declared the economic difficulties more disturbing than communication and logistic challenges. **Conclusion**: During cross-border care, immense challenges were faced by them, requiring efficient socioeconomic support and parental support groups.

Keywords: Socio-Economic challenges, Childhood cancer, Cross-border care, Low-middle income countries

INTRODUCTION

Childhood cancer care is being faced with multiple challenges due to poor access to early and correct diagnosis and treatment which is crucial for their better survival. Poor treatment outcomes

of children with cancer in low-middle-income countries (LMIC) result from defective mechanisms in their care pathways from diagnosis to referral for treatment, and follow-up.

The extent of missed diagnoses, under-diagnoses, or delayed diagnoses is directly connected to inadequate healthcare infrastructure and service delivery. Many LMICs have a paucity of trained multidisciplinary teams and reduced childhood cancer awareness, health education, and information among the public and healthcare professionals. These barriers are enhanced further by poor socioeconomic support and financial risk protection.[1]

The inequity in outcomes of children resulting from delayed detection, referral, diagnosis, and treatment in LMIC corresponds to global socioeconomic, health infrastructure, and trained workforce inequalities. Childhood cancer survival can be improved by gradually improving the quality, access, and coordination of healthcare services in all but mainly rural populations in LMICs.[2] The challenges of children with cancer from war and conflict areas during their diagnosis, treatment, and continuous care need to be addressed with the support of international communities and NGOs. To support the health of displaced people is a challenge shared by the health system in the host countries, intensified by their political instability and economic decline. These challenges were escalated with travel restrictions between countries during the COVID-19 pandemic. Although estimates of childhood cancer cases are not available, it is assumed that there is a high prevalence of advanced and unrecognized cancer cases in all age groups fleeing from low-income countries in humanitarian crises.[3]

The quality of life of these families of the children with cancer being treated in neighbouring countries should be enhanced by devising comprehensive family-centered care plans by the receiving countries. There are very few studies done in the region to explore these challenges experienced by these families while taking care of their children in the neighbouring countries.[4] Children's Hospital Lahore, offers Afghan children diagnosed with cancer, curative and palliative care services free of cost and they are never refused these services despite resource-constrained settings. Their survival is affected by the long travel times required to reach the primary treatment center in Lahore.[5] Armed conflict in Afghanistan has continued for over four decades resulting in destroyed health infrastructure in the country resulting in many Afghans seeking cancer care in neighboring countries including Pakistan.[6]

This study aims to deep dive these challenges faced by them during the course of their treatment. Unfortunately, established comprehensive childhood cancer care centers, forcing them to travel to other countries to explore treatment options, complicating further the cancer ordeal. Research on evaluation of distress linked with childhood cancer and psycho-social needs is deficient in this region except for few studies done in Iran, Jordan, and Turkey to explore these challenges faced by these families during cross-border childhood cancer care.

MATERIALS AND METHODS

Study design: Cross sectional study

Setting: Paediatric Haematology/Oncology Unit, University of Child Health Sciences (UCHS), Children's Hospital Lahore Pakistan

Duration: The study was done from 1st January to 31st March 2023

Sampling technique: The sampling was done by a non-purposive convenient method and data was collected through face-to-face interviews based on a questionnaire developed and validated by two experts.

Sample size: 24 children

Inclusion Criteria:

Children of age 1-16 years old from cross-border and, on active chemotherapy for either leukemia or solid malignancies

Exclusion criteria:

1- Children with cancer on active treatment in Children's Hospital Lahore from Pakistani nationality

2- Children on follow-up care

3- Children on palliative care

Data collection procedure

The study was done by conducting interviews with Afghan caregivers of these children to explore their socioeconomic hurdles, financial and communication difficulties, and effect of this illness on these families and their hopes of cancer cure. Interviews were conducted with twenty-four families: fathers, grandfathers, elder brothers, or mothers of children under treatment aged 24–65. Their children were aged 2–16 years. Majority of the fathers were laborers, daily wagers, who were either illiterate or had elementary education. These children were diagnosed with Rhabdomyosarcoma, Acute lymphoblastic leukemia, or Wilms tumor. Approval from the Institutional Ethical Review Board was obtained prior to starting the study and consents obtained from the parents and caregivers for enrolment in the study. One of the fathers volunteered to provide the services of a translator free of cost throughout the interviews. Parents of those children actively treated were included and parents not willing for interviews were excluded. Interviews were conducted and data analysis done by SPSS 26.

RESULTS

The study included children with mean age of 7.4±4 years and majority were males 79%. The main languages were Pushto (45%) and Dari (55%). Fifty percent understood considerably basic Urdu, 25% understood well and 25% did not understand at all. These families travelled from different states of

Afghanistan including Kabul, Herat, Jalalabad, Khust, Mizar shah, Ghazni, Baglan, Kandhar and others with a mean distance of 1340 Km.

Table 1: Demographic profile of Afghan children with cancer (N=24)

Characteristics	Domain	Category	n (%) or Value
Demographic Profile	Age (years)		7.4 ± 4.24
	Gender	Male	19 (79.0%)
		Female	5 (21.0%)
	Mother Language	Pushto	11 (45.0%)
		Dari	13 (55.0%)
	Number of siblings (median)		6
	Monthly income (median)		10,000 PKR
	Diagnosis	ALL	16 (67.0%)
		Solid Tumors	8 (33.0%)
	Youngest sibling age (mean) and median		3.8 years
	Distance to CHL (mean) and median		1340 KM and 1250 KM
	Total Travel Hours (mean)		27 Hours
	One Trip Cost (mean)		13,000 PKR
Communication Barriers	Understand Urdu	Little	12 (50.0%)
		Yes	6 (25.0%)
	Converse Urdu	Yes	3 (12.5%)
	Converse English	Yes	0 (100.0%)
	Translator Available	Yes	4 (16.6%)
	Communication Urdu	Very Difficult	12 (50.0%)
		Difficult	9 (37.5%)
		Not Difficult	3 (12.5%)
	Barrier	Mild	4 (16.6%)
		Moderate	6 (25.0%)
		Severe	14 (58.4%)
Impact on Family Dynamics	Accompanied by	Father	11 (45.8%)
		Mother	1 (4.2%)
		Parents	6 (25.0%)
		Elder Sibling	6 (25.0%)
	Siblings care	Grandparents	14 (58.4%)
		Mother	7 (29.1%)
		Themselves	3 (12.5%)
	Schooling	Affected	12 (50.0%)
		Stopped	3 (12.5%)
		No Effect	5 (20.8%)
		Not Schooling	4 (16.7%)
	Expenses by	Themselves	3 (12.5%)
		Others	21 (87.5%)
	Emotional	Neglected	20 (83.4%)
		Distressed	4 (16.6%)

Most of the children 67% were on ALL treatment, they needed to stay longer for the intensive phase of chemotherapy in contrast to solid tumors with a paucity of translation facilities with the healthcare providers' team. Table 1 depicts the effects on family dynamics due to the long stay of the child with cancer away from home accompanied by the main breadwinner of the family away from home, siblings' schooling, and compromised care of the rest of the family during this ordeal. The family dynamics are significantly affected financially, emotionally, and socially as shown by most of their families being dependent on relatives, neighbors, and community members for financial matters along with a marked effect on siblings' schooling during this duration. (Table 1)

Figure 1 shows the challenges these families have had in arranging a proper shelter for the patient and chaperons during the visits to Children's Hospital Lahore though most of these families were unable to afford to go back home sooner than a year. Figure 2 summarizes the financial burden and daily unmet needs of these families as 96% of families borrowed money at various times for daily expenses, food, and other needs.

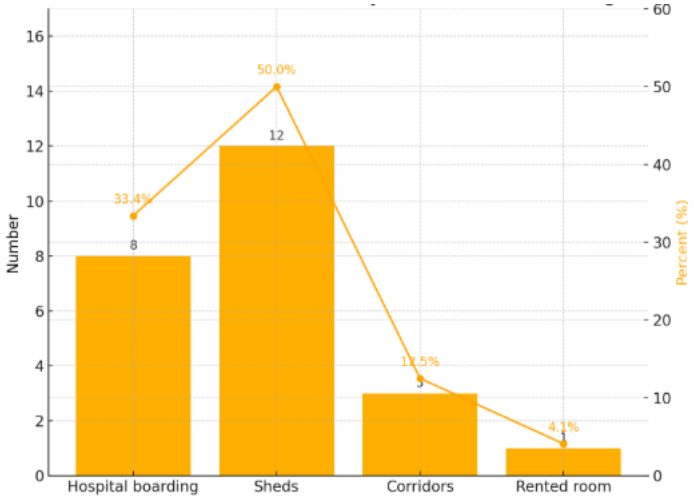

Fig. 1: Family lodging

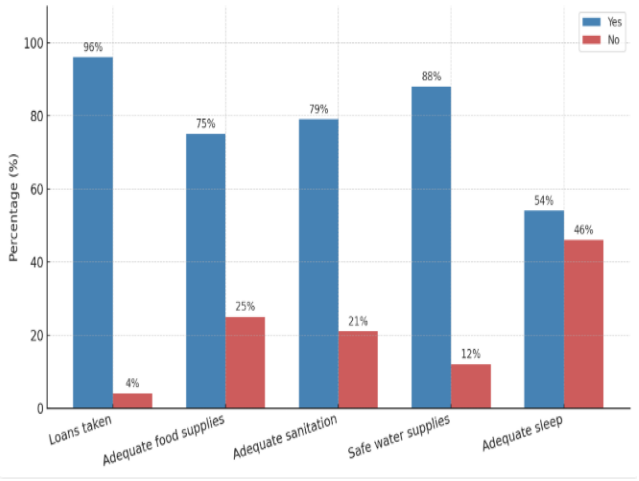

Fig. 2: Household material hardships HMH

DISCUSSION

In the present study, these children had acute lymphoblastic leukemia (ALL) in 67% and solid malignancies in 33% of cases as was the case for refugee children <18 years from Syria and Iraq being treated in Turkey, Lebanon, and Jordan with Leukemia being most common among these children.[7] We analyzed the extent of challenges faced by these families travelling from Afghanistan to Lahore Pakistan to get treatment for their children diagnosed with cancer. These children were treated with equity with local children and provided all the treatment facilities free of cost and without any external funding provided by foundations as described in many studies done in Jordan,

Lebanon, and Turkey.[7] Syrian refugees in Turkey have access to cancer care services free of cost and after completion of the treatment course, they leave Turkey and go back to Syria as there is disrupted healthcare services locally, like Afghanistan due to ongoing war crisis in these countries. The increased diagnostic interval documented could be due to the migration and registration process, financial burden, and reduced health literacy.[8,9]

Childhood cancer results in increased psychological distress for families, directly associated with parents having children with cancer facing financial issues in Lebanon[10], requiring social support and coping strategies to maintain optimism and family integration compared to patients even treated in their own countries or abroad.[11] Parents need coping mechanisms to deal with Psychosocial and marital distress and impaired family functioning integrating social support and better communication for parental emotional problems.[12,1] There are multiple factors related to depression diagnosed among mothers of children having cancer were linked with social factors like marital status, parental literacy, income, children cancer diagnosis), and stress factors (care-giving burden, cancer-related and general stress) requiring emotion-focused coping and perceived social support and other suitable effective preventive approaches along the course of illness.[14,15] These families have had a median monthly income of only 10,000 Pak Rupees with a median number of six siblings and the youngest child of 3.8 years mean age and 29% of these children were accompanied by the mother and 58% were taken care of grandparents at home followed by mother (29%), and siblings (13%) indicating the extent of familial dynamics disruption and stress. In 50%of cases, siblings' schooling was affected and 13% stopped schooling due to this ordeal. 83% of the families claimed that the emotional well-being of family members back home has been affected and 17% feel distressed. Family domains were affected badly as 88% of families were financially dependent on relatives, neighbors, and community members for daily expenses and 71 % of siblings were taken care of by grandparents or themselves alone unsupervised by parents or relatives.

A study was done to identify the increased emotional stress faced by children with cancer, caused by multiple factors including lack of provision of psycho-social support as most patients come from faraway places with paucity of basic health facilities. Surprisingly the siblings showed better emotional health Pediatric Emotional Distress Score (PED) was less than 28 (mean 23.4), probably related to the joint family system with grandparents greatly involved in childcare. About one-third of siblings had their anxiety scores above the clinical threshold emphasizing the significance of psycho-social support to all family members including the children with cancer.[13] Siblings' resilience is well documented, but mechanisms should be explored to define and implement sibling support programs accessible to these families independent of socio-demographic factors like ethnicity, financial burden, and parental education to improve siblings' Psychosocial well-being.[14-16]

The psychological stress experienced by caregivers of children related to their diagnosis is well documented.[17] Domains of caregiver psychological adjustment ranging from depression, anxiety, and post-traumatic stress

symptoms and stress resulting from general life stress, child's treatment-related stress, their perceptions of treatment intensity, and life threat directly or indirectly related to cancer diagnosis.[18] A study done in Singapore demonstrated practical, emotional, and cognitive problems being related with distress in non-resident caregivers and these problems could arise being dislocated from their home country.[19] A study was done in Iran's public sector hospital for assessment of stress in mothers of children being treated for acute lymphoblastic leukaemia explored the relationship between the availability and satisfaction of social support and caregiver burden (CB) and described that the greater the social support, the lesser the burden for caregivers despite caring young children and prolonged treatment durations.[2]

Among these challenges, logistics travelling from different provinces to Lahore Pakistan with a mean travel of 1340Km (1250 KM median) and a mean travel time of 27 hours and one trip costing them 13000 PKR, while 35% of children and families travelled <200 Km and 56% families 200-500Km and only 9% had to travel >500Km to reach the primary treatment center in a study done in Lahore Punjab Pakistan.[16] There are many patients with cancer within Afghanistan who are currently forced to travel long distances to get treatment elsewhere. The arduous journey is due to ongoing conflict in different regions of Afghanistan. As they often travel with several relatives, increasing total expenses and resulting in family dynamics disruption back home. Pakistan Afghan border control /immigration process allows them to enter Pakistan for a limited period increasing their difficulties in completing long courses of treatment and follow-up and overall outcome assessments of patients including pediatric cohort (20.3%).[6]

Syrian refugees preferred to travel to Turkey where free treatment services were available in public sector hospitals for children with cancer though many also travelled to Jordan and Lebanon where they were obligated to pay treatment costs partially as they were exposed to disrupted healthcare in their own country due to war and armed conflicts since 2011. These children arrived in advanced stages of cancer due to multiple factors such as local inadequate healthcare services, poor referral pathways, communication barriers, inadequate transportation means, and reduced income to seek medical help. They documented inferior outcomes with overall survival less than Turkish children in the same hospitals.[9] Another study done in Jordan highlighted the increased load of children cancer in the displaced populations in Jordan and explored their dynamics and success of lifesaving initiatives for children being treated in Jordan displaced from Syria, Palestine, Iraq, and Yemen at The King Hussein Cancer Center (KHCC) and Foundation (KHCF) in partnership with the St. Jude Children's Research Hospital, treating 968 non-Jordanian children with cancer since 2011-2022. Such pediatric cancer care models and continued funding mechanisms are required for sustainable availability of cancer care services for displaced communities.[21]

The Household Materials Hardships (HMH) review revealed that 96% took loans despite this they were unable to have adequate lodging, appropriate food, safe portable water, and safe sanitation practices. 33% were able to get a

place in hospital boarding and the rest slept in sheds (50%) and corridors (12%), and only one family rented a room during their stay for the treatment course. Another study done in Children's Hospital Lahore described 58% of parents took loans and 68% borrowed money while treating their children with cancer.[16] One of the most consistent barriers to accessing healthcare facilities among stigma, culture, and communication was financial challenges with limited disposable incomes of these families requiring improved funding mechanisms by foundations currently focusing on the communicable disease spectrum of children globally need to be sought out to save more lives.[7,22] Atun et al[1] explored the current evidence on financial challenges related to childhood cancer globally, describing the current definitions and assessment, their components, and the extent of variations by country income. The domains of financial hardships reported included medical (clinical labs, procedures, and supportive care) and non-medical (accommodation, transport, travels, utilities, food, educational fee) out-of-pocket expenses, indirect costs (lost daily wages, income, jobs, neglecting children and household) various monetary coping mechanisms, psycho-social and behavioral trends, and adjustments in LMIC and compared with High-income countries (HIC). They concluded that there is an essential need to implement an evidence-based tools with validated interventions to devise effective policies enabling to tackle economic adversity in children cancer which is a leading factor towards poor health outcomes and survival disparities worldwide.[23]

Only12% of families were able to converse in Urdu,50% understood basic Urdu, and neither did they know English to communicate with hospital staff and a translator facility was available for only 16%. 50% found it very difficult to communicate in Urdu with healthcare providers and 37% moderately difficult. 58% perceived the communication barrier as severe, 25% moderate, and 17% mild. These families spoke either Pashto or Dari.[6] Studies done in Turkey for refugees from conflict countries showed that once these families reached there after a great ordeal, they faced many challenges like registration in an appropriate comprehensive healthcare facility, communication barriers, lodging, provision of good nutrition, and safe sanitation to children with cancer on treatment despite legal regulations in place from the local Governments.[7,9]

A huge incursion of resources is required to precisely evaluate the cancer burden and to facilitate improved comprehensive cancer care in LMIC having humanitarian crises. There are opportunities to upgrade cancer care in such situations, including empowering refugees and host community perspectives and developing a precise policy framework for cancer care in humanitarian conflict populations.[24] The long and challenging cancer journey of these patients, with uncertain follow-up courses is very irksome. The lack of a cancer healthcare capacity in Afghanistan after many years of conflict should promote initiatives to build infrastructure and strengthen health systems by policy makers to support post-conflict local, national, and cross-border cancer care.[25] Global Policymakers and politicians should identify and prioritize socioeconomic inequities strongly affecting cancer outcomes as a global public health issue, especially in places where these disparities are growing, bringing advanced

preventive and curative cancer interventions accessible to all.[26] According to one of the WHO report Afghanistan's health system is on the edge of collapse. There is a need for urgent action to be taken to prevent the country from facing an imminent humanitarian crisis and to identify methods to scale up health response by engaging stakeholders.[27]

CONCLUSION

These families of children with cancer being treated cross-border are facing immense challenges requiring efficient Socio-Economic support and the need for the availability of dynamic parental support groups to lessen the severity of their long ordeals cannot be overemphasized.

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