The Health Needs of Refugee Children: Children with Cancer

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Global cancer burden

- Cancer and cancer care are increasingly recognized as a major worldwide challenge given their global, financial, social and health implications.
- The prevalence of cancer is increasing in all countries.
- Of the 14 million people diagnosed with cancer worldwide in 2012, more than 60% live in low and middle income countries (LIC/MIC).
- 70% of the cancer deaths worldwide occur in LIC/MIC as well.
- Global cancer incidence is predicted to reach 25 million by 2030, 70% of which is expected to be reported in developing countries.

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- 83% of the world’s population live in low and middle-income countries.
- 90% of the world’s children live in low and middle-income countries, and where access to care is poor.
- 84% of childhood cancers occur in low and middle-income countries.
- These countries have younger median ages and higher proportions of children in their populations (27% of the population of middle-income and 40% in low-income countries) than do high income countries (17%).
- 148 000 cancers/year in children occur in less-developed regions, in contrast to 28 000 children with cancer in more-developed regions. (GLOBOCAN, 2008)
CHILDHOOD CANCERS

- Childhood cancers constitute 2-4% of all cancers.
- Childhood cancers are different than adult cancers
- Early diagnosis & appropriate treatment → Survival 70%
- 1/900 adults are childhood cancer survivors

TURKEY

- Population: 76 million
- Higher middle income
- < 18 years old: 36%
- < 15 years old: 24%
- Incidence of cancer is 227 per 100,000 for adults (175,000 new patients/year)
- 120 per 1,000,000 for children (2500-3000 new children with cancer/yr)

Turkish Pediatric Tumor Registry,

Survival Rate (7 Year)
Survival in childhood cancer in Turkey

- Five-year survival rate in children with cancer in Turkey is reported as 65% [20-22].
- Higher survival rates are reported in specific cancer centers.
- Among 2413 patients, mostly solid tumors, diagnosed and treated between 1990-2012 in the Istanbul University, Institute of Oncology, Division of Pediatric Hematology-Oncology, the 5-year survival rate is reported as 74%.

### Causes of mortality in Turkey

<table>
<thead>
<tr>
<th>Causes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adults</strong></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular diseases</td>
<td>39.9%</td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td>20.0%</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>25.1 %</td>
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<tr>
<td>Cardiologic reasons</td>
<td>20.8 %</td>
</tr>
<tr>
<td>Trauma</td>
<td>13.9 %</td>
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<tr>
<td><strong>Cancer</strong></td>
<td>7.2 %</td>
</tr>
</tbody>
</table>

Cancer in the Middle East

- Middle East includes countries from North Africa to central Asia.
- This region includes a wide spectrum of economically diverse countries, from technically advanced countries with high level cancer care to countries with little or no cancer treatment capabilities.
- There are large discrepancies in population size, wealth and health expenditure and availability of quality of treatment. The relative overall cancer survival rate can be around 60% in some, however it is only 30% in most.
- The conflicts, war in some of these countries in the region affect cancer care as well as many other public health issues.
- Treatment of non-communicable diseases such as cancer in refugees is of increasing importance because the number of refugees is growing.
- Cancer in refugees causes a substantial burden on the health systems of the host countries. Recommendations to improve prevention and treatment include improvement of health systems through standard operating procedures and innovative financing schemes, balance of primary and emergency care with expensive referral care, development of electronic cancer registries, and securement of sustainable funding sources.
- Analysis of cancer care in low-income refugee settings, is needed to inform future responses.

Cancer in refugees in Jordan and Syria between 2009 and 2012: challenges and the way forward in humanitarian emergencies.


1 Office of the United Nations High Commissioner for Refugees, Geneva, Switzerland. 2 Office of the UNHCR, Damascus, Syria. 3 Department of Neurology, Massachusetts General Hospital & Harvard Medical School, Boston, USA.

- The UNHCR, through exceptional care committees (ECCs), developed standard operating procedures to address expensive medical treatment for refugees in host countries, to decide on eligibility and amount of payment.
- Data from funding applications for cancer treatments for refugees in Jordan and Syria between 2009 and 2012 were evaluated.

**Approvals and funding**

- Only 246/511 (48.1%) applications for cancer were approved and funded.
- The main reason for denial (52%) was poor prognosis.
- The mean amount requested per application was $11,540 in 2011, $5,151 in 2012 ($289–141,253).
- The mean amount that was approved per application was $4,626 in 2011, and $3,501 in 2012 ($289–21,188).
- For those approved, the full amount was given in 49 (73.1%) cases in 2011, and in 59 (66.3%) cases in 2012.
- In Syria, the average cost per cancer treatment was $3,978 in 2010, and $4,981 in 2011.
- Lack of funds was one of the main reasons for denial.
Turkey’s health system

- At the beginning of the millennium, the performance of Turkey’s health system in terms of public health, insurance of the patients, and the patient satisfaction was at the bottom of the Organisation for Economic Co-operation and Development (OECD) countries and in the European Region of World Health Organization (WHO).

- Turkey has undertaken the Health Transformation Program (HTP) from 2002 on, including major reforms to transfer and improve the health system and its outcomes and the situation has improved.

- All cancer care and treatment is provided free of charge.

Cancer Care to Foreigners in Turkey

- Multidisciplinary cancer treatment in Turkey is quite advanced in comparison to most countries in the region.
- Some cancer patients from some Middle East countries, Balkan countries and Turkic origin or Turkic speaking countries in the northeast of Turkey such as Azerbaijan, Kazakhstan, come to Turkey for an accurate diagnosis and/or treatment, they also come for transplantation.
- Some of these patients come to private hospitals that have cancer centers and/or transplantation units.
- There are also refugees coming to Turkey from neighboring areas of conflict.

Cancer Care to Refugees in Turkey

- Since the onset of the civilwar of Syria in March 2011, over 2 million Syrians have come to Turkey according to Government estimates.

- Since the beginning of the crisis in 2011, Disaster and Emergency Management Residency (AFAD), an organization activated for crisis circumstances promoted ordinary daily life, regular education facilities, and health services.

- In April 2013, Turkey put its first asylum law, the “Law on Foreigners and International Protection” regulating all proceedings for refugees living in Turkey.

Since the onset of the civil war of Syria in March 2011, over 2 million Syrians have come to Turkey (1.6 million according to Government estimates in November 2014).

In Turkey, in regions that are close to the Syrian border, 1.2 million people have been added to the existing native population of 10 million.

85% of Syrians are living outside the camps.

From the camps where Syrians live, there were over 500,000 referrals to the hospitals.

There have been 35 thousand births within the Syrians according to data from the ministry of Health (it is estimated that this value is over 60 thousand when Syrians not living in camps are taken into account).

In Turkey, in regions that are close to the Syrian border, in government hospitals 30-40% of the patients are Syrians., leading a financial and capacity burden in these hospitals.

4.5 billion dollars have been spent for refugees during April 2011-November 2014 (UN and European funding 246 million dollars).
Cancer Care to Refugees in Turkey

- According to AFAD survey, about **10% of refugees report problems with non-communicable diseases**, including hypertension, diabetes, cancer, asthma, and renal failure [69].

- Over the last four years, the financial requirements for United Nations High Commissioner for Refugees (UNHCR)'s operation in Turkey have increased dramatically.

- Refugees with cancer can be treated at tertiary government and university hospitals free of charge. They usually have very advanced stage diseases at **diagnosis**, so that they have poor outcome.

- Turkey also has seen **an important increase in the number of non-Syrian asylum applications** over two years mainly from Iraq, Iran and Afganistan. It is estimated that there are **over 100,000 refugees in Turkey in 2014, not including Syrians**.

- **It is estimated that 240 new childhood cancer cases each year are to be diagnosed within the Syrian population in Turkey.**

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We conducted a survey on the demographic data, treatment and outcome of cancer in refugee children in Turkey during March 2013-October 2015.

17 Pediatric Hematology-Oncology Centers located in 10 different cities participated in the study.

212 children with cancer were evaluated retrospectively.

Problems identified by health care personnel and families were evaluated.
CANCER IN SYRIAN REFUGEE CHILDREN IN TURKEY

- CANCER IN SYRIAN REFUGEE CHILDREN
CANCER IN REFUGEE CHILDREN IN TURKEY

DEMOGRAPHIC DATA

- 212 children
- Male: female ratio was 1.5
- Median age was 5 years (1-17 years)
- 197 patients from Syria
- 7 patients from Iraq (5 treated in Central Turkey, 2 in Istanbul)
- 8 patients from OTHER regions
Distribution of 212 refugee cancer patients according to Nationality

n=197 (92.7%)
Distribution of 212 refugee cancer patients according to Diagnosis

- Acute leukemias: n=52 (24.5%)
- Lymphomas: n=31 (14.6%)
- Brain tumor: n=29 (13.6%)
- Neuroblastoma: n=21 (10%)
- Bone Tumor: n=13 (6.1%)
- RMS: n=13 (6.1%)
- Wilms: n=13 (6.1%)
- Germ Cell Tumor: n=35 (16.5%)
- Retinoblastoma: n=31 (14.6%)
- Hepatoblastoma: n=10 (4.8%)
- Langerhans CH: n=10 (4.8%)
- NPC: n=5 (2.4%)
- MM: n=5 (2.4%)

Diagram showing the distribution of cancer patients by type.
CANCER IN TURKISH CHILDREN AND IN REFUGEE CHILDREN IN TURKEY: DISTRIBUTION OF DIAGNOSIS


<table>
<thead>
<tr>
<th>Tumor type</th>
<th>Turkish children (2002-2008)%</th>
<th>Refugees (2013-2015)%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I-Leukaemia</td>
<td>31.7</td>
<td>24.5,0</td>
</tr>
<tr>
<td>II-Lymphomas</td>
<td>17.1</td>
<td>16.5</td>
</tr>
<tr>
<td>III-Brain tumors (CNS)</td>
<td>13.3</td>
<td>14.6</td>
</tr>
<tr>
<td>IV-Neuroblastoma</td>
<td>7.5</td>
<td>13.6</td>
</tr>
<tr>
<td>V- Retinoblastoma</td>
<td>3.1</td>
<td>1.8</td>
</tr>
<tr>
<td>VI-Renal Tumors</td>
<td>5.5</td>
<td>6.1</td>
</tr>
<tr>
<td>VII-Hepatic tumors</td>
<td>1.4</td>
<td>0.9</td>
</tr>
<tr>
<td>VIII- Malignant Bone tumors</td>
<td>6.0</td>
<td>10.0</td>
</tr>
<tr>
<td>IX- Soft tissue sarcomas</td>
<td>6.5</td>
<td>6.1</td>
</tr>
<tr>
<td>X- Germ cell tm</td>
<td>4.5</td>
<td>2.8</td>
</tr>
<tr>
<td>XI- Carcinomas and other epithelial ca.</td>
<td>2.7</td>
<td>1.3</td>
</tr>
<tr>
<td>XII- Other</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><em>(n=11898) 100,0</em></td>
<td><em>(n=212) 100,0</em></td>
</tr>
</tbody>
</table>
Distribution of 212 refugee cancer patients according to treatment regions in Turkey

- Mediterranean Sea region: n=97 (45.5%)
- Marmara region: n=42 (19.8%)
- South East and East Anatolian region: n=47 (22.1%)
- Central Anatolia: n=42 (19.8%)
- Eagean region: n=47 (22.1%)

*Note: The values in parentheses represent the percentage of the total patient count.*
Children with cancer treated in Turkey since 2012
According to cities/regions

212 patients are treated:

• 97 patients in the Mediterranean Sea Region (Adana-2, Kahramanmaraş, Mersin)
• 42 patients in the Marmara region (Istanbul-5)
• 47 patients in the South East and East Anatolian region (Urfa-2, Gaziantep-2, Diyarbakır)
• 18 patients in Central Anatolia (Ankara, Konya)
• 8 patients in the Eagean region (İzmir)
CANCER IN REFUGEE CHILDREN IN TURKEY

OUTCOME: 159 patients are alive (NED± AWD), 31 have died, 22 lost to follow up
CANCER IN REFUGEE CHILDREN IN TURKEY

OUTCOME: 212 Children

Mediterranean Sea Region;
  97→75 (77%) patients alive, 12 died, 10 lost to follow-up
South East and East Anatolian region;
  47→38 (80%) patients alive, 6 died, 3 lost to follow-up
Marmara region;
  42→31 (73%) patients alive, 8 died, 3 lost to follow-up
Central Anatolia;
18→10 (55%) patients alive, 2 died, 6 lost to follow-up
Egean region;
  8→5 (62%) patients alive, 3 died
REFUGEE CHILDREN IN TURKEY UNDERGOING HEMATOPOIETIC STEM CELL TRANSPLANTATION (HSCT) FOR CANCER AND HEMATOLOGICAL DISEASES

- 15 patients
- 9 patients due to nonmalignant diseases (aplastic anemia, Thalassemia major, etc.)
- 6 patients due to cancer
  - 3 autologous (1 NBL, 1 HD, 1 Ewing) HSCT
  - 3 allogeneic (1 NHL, 1 AML, 1 ALL) HSC

Outcome: 11 are alive, 4 have died
PROBLEMS IDENTIFIED BY HEALTH CARE PERSONNEL AND FAMILIES DURING DIAGNOSIS AND TREATMENT IN REFUGEE CHILDREN WITH CANCER

1. Accommodation
2. Social and psychological problems: adaptation to a new setting, to the burden of disease
3. Language barriers
4. Compliance with therapy
5. Hygiene (personal hygiene, hygiene at home)
6. Communication problems within families and health care personnel
7. Lack of donors for transfusion especially in transplantation
8. Access to medication as outpatients
9. Poor prognosis due to advanced disease at diagnosis and relapsed disease (delay in diagnosis, not able to come in time due to conflict in the area)
10. (Financial problems)
PROBLEMS IDENTIFIED BY HEALTH CARE PERSONNEL AND FAMILIES DURING DIAGNOSIS AND TREATMENT IN REFUGEE CHILDREN WITH CANCER

1. Accommodation: Hygiene is very important for kids with cancer. The hygiene in the camps or prefabric houses is not adequate most of the time. So, most patients want to stay longer than necessary in the hospital. Some families want to travel back and forth to their home in Syria, however they have delays in returning to the hospital or may not return due to war.

2. Social and psychological problems: adaptation to a new setting, to the burden of disease

3. Language barriers: Although a translator/translation service by phone has been provided by the Turkish government, most of the time this is not adequate.

4. Compliance with therapy is poor, usage of oral drugs in the camp or at home is not reliable, some do not come to treatment at the planned date

5. Hygiene (personal hygiene, hygiene at home): hand washing, clean food, clean water, adhering to hygiene rules is poor

6. Communication problems within families and health care personnel: Some parents do not want to share the room with a family that does not adhere to hygienic measures.

7. Lack of donors for transfusion: Especially in transplanted patients lack of adequate donors is important.

8. Access to medication as outpatients: As inpatients medication is provided in the hospital. As outpatients providing the medication takes longer. This is trying to be solved by finding medication left from other patients, by extending the inpatient stay in the hospital. By finding support from volunteer organizations.
CONCLUSION

REFUGEE CHILDREN WITH CANCER

• Health care, education and food aid for Syrian (and other) refugees in Turkey is provided, and health services are given free of charge in the standard of Turkish citizens.

• Socio-economic and accommodation problems of the families is tried to be solved by extending the inpatient hospital stay.

• Although most children come with advanced stage and some with relapsed disease, the treatment outcome is satisfactory in parallel to stage.

• Hygiene, language barriers, compliance, are major problems.

• Preliminary results of this survey may help to inform future responses in children with cancer who are forced to migration.
ACKNOWLEDGEMENT TO 17 PARTICIPATING PEDIATRIC HEMATOLOGY-ONCOLOGY CENTERS IN THE SURVEY OF CANCER IN REFUGEE CHILDREN IN TURKEY

- Cukurova University Medical School, Adana
- Adana Government Hospital, Adana
- Gaziantep Government Hospital, Gaziantep
- Gaziantep University, Gaziantep,
- Harran University, Sanliurfa,
- Sanliurfa Children’s Hospital, Sanliurfa,
- Sutcu Imam University Faculty of Medicine, Kahramanmaraş,
- Mersin University Faculty of Medicine, Mersin,
- Diyarbakır Children’s Hospital, Diyarbakır
ACKNOWLEDGEMENT TO 17 PARTICIPATING PEDIATRIC HEMATOLOGY-ONCOLOGY CENTERS IN THE SURVEY OF CANCER IN REFUGEE CHILDREN IN TURKEY

- Ankara Child Health Hematology Oncology ERH, Ankara
- Selcuk University, Konya
- Dr. Behcet Uz Children’s Hospital, Izmir
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- Istanbul University, Oncology Institute Istanbul,
- Okmeydanı Education and Research Hospital, Istanbul
- Sisli Etfal Education and Research Hospital, Istanbul
- Medeniyet University,Istanbul

ERH= Education and Research Hospital