

# Caring for children with cancer evacuated from Ukraine: the patients' perception

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## Abstract

**Background and Aims.** Since the war in Ukraine which began on February 2022, many pediatric oncology centers have welcomed patients from Ukraine. To understand the needs of patients and families arriving at our hospital, an anonymous questionnaire investigated the families' backgrounds, feelings and impressions about hospitality and care. **Methods** Twenty items investigated how patients had reached Italy, from whom they received help (logistically/economically); emotions regarding their status as war refugees; knowledge, expectations, and opinions about Italy and Italians; the quality of medical care received and relationships with the healthcare staff; suggestions to improve assistance. **Results** Questionnaires were completed by 19/32 patient/parents in the time interval May-November 2022 in two different pediatric-oncology centers in the north of Italy. Most families had reached Italy (58%) and received medical care (95%) thanks to the help of Charities and the Italian Public Health Care System. Many of them (69%) declared themselves to be satisfied by the assistance. The Italian population appeared friendly (95%) and generous (58%). The improvement of their stay correlated with the positive outcome of their children (15%), the presence of the whole family (15%), the end of the war (10%), and the overcoming of language barriers (10%). **Conclusions.** Taking care of children from a different country suffering the traumatic experience of fleeing their country in addition to the equally traumatic condition of cancer disease, is a huge task. Our questionnaire aimed at obtaining a better understanding of families' conditions, not at bridging the relational gap due to different culture and experiences.

## INTRODUCTION

One of the main consequences of armed conflicts on children and their families is the need, in many cases forced, to leave their country. At the end of 2022, the United Nations High Commissioner for Refugees (UNHCR) estimated that the number of people forced to flee their countries amounted to 108.4 million.<sup>1</sup> This number included refugees, asylum seekers, internally displaced persons and others who required international protection but were not included in those protected by UNHCR. Of these, 40% were children.

It was estimated that more than 5.9 million Ukrainian refugees have found shelter in neighboring countries (as of December 31, 2023), and that more than 5 million Ukrainians are displaced within their own country. The majority of refugees were women and children (the latter represent around 40% of the total quota), given the ban on male Ukrainian citizens leaving the country.<sup>2</sup>

Apart from common diseases and prevention activities that could become impaired during war times, children exposed to wars and fleeing from them are at greater risk of toxic stress, consisting of the repetition over time of extreme and persistent adverse events, in the absence of support and care.<sup>3</sup> These events may include the death of a family member, a life-threatening illness, a natural or man-made disaster, and terrorist attacks. Children may show a wide range of stress reactions that include specific anxiety, prolonged crying, disinterest in the surrounding environment, psychosomatic symptoms and aggressive behaviors.

The effect of the current conflict on pediatric cancer care in Ukraine and in countries receiving its refugees depends on many factors. First of all, the safety of patients and medical staff, the compliance with the basic requirements of therapeutic protocols, the prevention of human errors during medical procedures, the regulation of patient flows according to the intensity of combat, the use of medical or surgical interventions with minimal and manageable risk of complications.

During the early months of the conflict, a classification of war zones was proposed to help understand whether these tasks could be continued<sup>4</sup>.

Based on the available information, four zones were established regarding the feasibility of the oncological treatments: the first zone was that of active hostilities or humanitarian disaster, where no oncological treatment was possible and priority was given to the transfer of patients to facilities located in the fourth zone or in nearby available countries. In the case of particularly severe condition patients who required immediate stabilization, transfers were made to the second area. The second zone was at high risk of bombing or other humanitarian problems. The third zone, with medium probability of bombing, was a humanitarian alert zone. Finally, the fourth zone, where the probability of bombing was low, was defined as one of humanitarian stability. In the transition from zone 1 to zone 4, treatment gradually changed from impracticable to somewhat similar to what was offered prior to the conflict, with a progression of availability that started from the consultation and through diagnosis and transfer culminated in the treatment. In the transition between the first and second zones, medical care was carried out mainly on an outpatient basis. With transition to other areas it gradually became possible to increase the frequency of appointments and even create some places for hospital admission.<sup>4</sup>

Based on the Ukrainian epidemiological situation immediately preceding the conflict, it was estimated that, in the first months of the war, there were approximately 33,000 cancer patients (approximately 1% were pediatric) within the refugee population, distributed among neighboring countries in a non-uniform way.<sup>5</sup>

The devastation of war resulted in a delay in access to prescribed treatments, both for patients who remained in Ukraine and for those forced to emigrate and face slowdown in care due to their resettlement (both bureaucratic and healthcare).<sup>6</sup> One of the worst consequences of these delays may be the increase in cancer mortality, directly proportional to the extent of the delay and which affected all types of treatment.<sup>7</sup>

Soon after the start of the war, in Feb 2022, it rapidly became clear that we were faced with an enormous humanitarian crisis that also involved also children and adolescents with cancer obliged to interrupt their treatment.

The international paediatric oncology community has been trying to find ways and resources to deal with this emergency, and many paediatric oncology centres in Europe were asked to receive patients from Ukraine.

On March 7, 2022, the Lombardy Regional Authority granted free care for pediatric patients with cancer. The evacuation was coordinated by the establishment of a patient triage hub in Poland to ensure the safe and rapid transfer of children from Ukraine to appropriate medical facilities in other countries<sup>8</sup>.

The aim of this study was to evaluate the effect of the forced abandonment of their own country on the pediatric oncology population arriving from Ukraine in the period between May and November 2022, through questionnaires administered to the patients' mothers in two different pediatric-oncology centers in northern Italy, i.e. Istituto Nazionale dei Tumori, in Milan, and Policlinico San Matteo, in Pavia.

## PATIENTS AND METHODS

The specifically created questionnaires consisted of 20 questions, of which 16 closed and 4 open as illustrated in Table 1. The topics addressed concerned: a) the way in which the patients and their parent/s had reached Italy; b) the help received (logistical and economic); c) the emotions experienced regarding the status of being a refugee; d) previous knowledge, opinions and expectations regarding Italy and Italians. Finally, e) a judgment on the quality of care received and f) any possible advice to improve the care required were asked. The questionnaires were translated into Ukrainian and thereafter translated back into Italian by a professional mother tongue mediator.

The compilers signed a consent form, containing the information on the purposes of the study and the processing that the data collected would undergo. As the questionnaires were anonymous, we did not require approval from the Ethical Board but only assent for the whole project.

The questionnaires were proposed to all the families that arrived to our Units after the first two months of care, by volunteers and a one-week window was granted to return the questionnaires.

Mothers were allowed to fill out the forms together with their children should they so desire,, however we did not obtain data on this choice.

The questionnaire was prepared with a descriptive intent and not as a tool for drawing comparisons by means of statistical analyses therefore only descriptive statistics were used in results.

## RESULTS

Nineteen questionnaires were completed out of a total of 32 families who had received them. The age of the patients ranged from 0 to 17 years (median 11). The gender of the patients was not included among the questions in the questionnaire, but in the reference population the two components were exactly 50% each. Diagnoses were central nervous system (CNS) tumors in 10 cases, osteosarcoma in 5, neuroblastoma in 4, and different diagnoses in the remaining 13 patients as shown by table 2.

In order to classify the patients according to their estimated prognosis, we utilized different tumor-specific staging systems, i.e. the Chang system for CNS neoplasms, the INRGSS for neuroblastoma, the National Wilm's Tumor Study system for nephroblastoma, the TNM for osteosarcoma and Ewing's sarcoma, the Reese and Ellsworth system for retinoblastoma, the Ann-Harbor system for Hodgkin's lymphoma. For those tumor types for which a staging system was not available, the presence of metastases and resistance to previous treatments were considered as severe prognostic factors.<sup>9</sup> Patients were therefore divided into two groups according to these principles, as shown in Table 2.

Table 3 shows how the flight from Ukraine was managed from the very beginning of the conflict together with an opinion on the sustainment of care from the time patients were admitted to Italian hospitals.

Regarding the questions on the emotions felt upon arrival in Italy, 44% of the responders said that "hope" was their main feeling, followed by fear, sadness and relief in 16% of the cases.

As for prior knowledge about Italy, 42% of the responders said that they had already heard of Italy for its cities and monuments, 24% for famous films and actors, with only 12% having acquaintances or friends in our country. Seventy-four percent had a positive opinion of Italy prior to leaving Ukraine and 63% changed it for the better after arriving.

Sixty-three percent expected to be welcomed in Italy for a long period, necessary for the care of their children. Only 16% hoped to be able to move permanently, and in the free note section, they demonstrated a widespread desire, in the near or distant future, to be able to return to their homeland. Italians were perceived as kind (95%), generous (58%), and the quality most often mentioned was goodness (6/19).

Table 4 summarizes the attitude toward care received in Italy: most parents reported that they believed their children were cared with the same attention as Italian patients, and had good relationship with Italian healthcare staff and, in general, with the Italian population.

When asked if there were issues and possible improvements for their stay in Italy, respondents correlated amelioration with the positive outcome for their children (15%), the presence of the whole family (15%), the end of the war (10%), and the overcoming of language barriers (10%).

## DISCUSSION

According to UNICEF data, from the start of the war in Ukraine on 24 February to 30 March 2022, more than 2 million children were forced to leave the country due to the violence and dangers linked to the conflict.<sup>10</sup> Among these children and adolescents, there were also young cancer patients, particularly vulnerable to the risk of the interruption of treatment. To try to limit this detrimental effect, the SAFER-UKRAINE project was led by St. Jude Children's Hospital (specifically its non-profit arm, St. Jude Global), with the aim of creating an international humanitarian network to provide pediatric cancer patients with the ability to safely leave Ukraine. The aim was to reach specialized hospitals for their pathologies, mainly throughout Europe<sup>11</sup>. According to SAFER Ukraine sources, around 1300 children with various forms of cancer managed to leave Ukraine through this channel and find placement in specialized oncology centers in Europe<sup>12</sup>. The Fondazione IRCCS Istituto Nazionale dei Tumori, in Milan, and IRCCS Policlinico San Matteo, in Pavia, also joined this international solidarity network, making themselves available to welcome Ukrainian pediatric oncology patients and continue their treatments. The arrival of the refugee children quickly catalyzed attention on the need to take charge of complex situations, in which patients, in addition to their underlying pathology, brought with them a wealth of potentially traumatic experiences, requiring healthcare workers to respond quickly and effectively to articulated needs and requiring multidisciplinary skills. To better understand the needs of patients and families (usually made up of mothers alone or possibly other female members, given the ban on men leaving the country), an anonymous questionnaire was developed, which could act as a tool for studying the cultural and family backgrounds, needs, emotions and collect their opinions regarding treatment and reception.<sup>13</sup>

Worthy of note is that, despite the fact that the questionnaires were anonymous and there was no rush in filling them, we only obtained the complete forms from 59% of the mothers, maybe as a sign of fear of possible sanctions in case of "wrong" or unwelcome answers. While the financial support for treatment and the stay in Italy was and still is mainly borne by the "consortium" formed between the public health system and the charities (the Soletierre association coordinated the project involving the patients included in this work through the *DELIBERAZIONE N° XI / 6077 del 07/03/2022, Regione Lombardia*), 14% of families still believed in the possibility of being personally in debt with the organization.

It is significant to note how alongside hope (mostly linked to the clinical improvements of kids) there was also fear and sadness, as residues of the traumatic experience of forced and sudden flight from own country in addition to cancer experience<sup>14</sup>. As regards the emotions felt upon arrival in Italy, they were mainly characterized by an attitude of hope, both general and in the recovery or clinical improvement of their children, associated with a feeling of relief at having moved away from a dangerous situation (66% of the respondents). This fact represents a wealth of positive resources that are also important for children, who experience a relationship of mutual exchange with their parental figures, being influenced by and influencing their attitudes, thoughts, psychological state and ability to respond to stress<sup>15,16</sup>. However, around one mother in three also showed the emotions of fear or sadness, a residue of past traumatic experiences and the violence (direct or indirect) of war. In terms of the quality of the assistance received, overall satisfaction was evident, with a particular appreciation of the relationship established with healthcare personnel, which 95% of the respondents reported as positive. The theme of cure or improving the health of their children was nevertheless reported also after the question "what would allow you to enjoy your stay in Italy better?", both directly and indirectly (for example in answers such as "going home", which would imply improvement in children's health, or "being in Italy for holidays and not for treatment", with the same meaning).

The relationship with the Italian population was reported as positive and Italians described as welcoming, kind and generous. This aspect also represents an important point in determining the adaptation and resilience capabilities of children and parents. The absence of episodes or manifestations of intolerance and/or hostility facilitates integration for the immigrant and/or refugee population into the social context and the

creation of social support networks, avoids isolation and the feeling of alienation<sup>17-19</sup>.

This investigation allowed us to focus on points that clinical practice had most highlighted as difficult. The interest in understanding the main barriers to effective communication between healthcare professionals and patients began from the fundamental issue of reconstructing their clinical history and current state of health. At the beginning of the flight from Ukraine, treatment plans and imaging were very often lacking or not translated, thus the resulting confused relationship could exclude families from control over their children's health status<sup>20</sup>. Knowledge of information useful for reconstructing the cultural and psychological profile of both patients and family members, their hopes, expectations, needs and criticisms, could allow for better collaboration and therapeutic alliance.

In our opinion, the questionnaire tool could achieve this objective, providing a qualitative investigation method capable of obtaining a deeper understanding of the phenomenon and taking the point of view of the participants in the study<sup>21</sup>. A questionnaire is also certainly an advantageous tool from the point of view of costs and time, as it can be self-administered (i.e. completed independently by the respondent, at a time following administration) and does not require particular technological support to be completed. It also provides indications that are easy to interpret and quickly applicable to the clinical context.

The welcoming of any refugee is undoubtedly a bilateral process, which requires an investment in communication, relationships and knowledge and which can make positive use of mutual listening. It is therefore necessary to have awareness and consideration of differences, but also closeness and understanding of the other's human experience, with the common aim, in our case, of achieving the best possible assistance.

## TABLES LEGENDS

**Table 1.** The questionnaire administered

**Table 2 .** Ukrainian patients admitted to Istituto Nazionale dei Tumori, in Milan and Policlinico San Matteo, in Pavia, and their estimated prognosis

**Table 3.** How the flight from Ukraine was managed and opinions on the sustainment of care

**Table 4.** Attitude toward care received in Italy

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