The program of multidisciplinary online support of children with spina bifida in Ukraine during the war


Abstract. Background. The Russian aggression against Ukraine has exacerbated the challenges faced by children with spina bifida (SB). Access to healthcare is severely impacted due to security concerns, restricted mobility, and mass displacement. To address these issues and improve access to medical care, we launched a project titled “The program of multidisciplinary online support of children with spina bifida in Ukraine”. The aim: to present the program of multidisciplinary online support of patients with SB and their families during the war for improving healthcare for this vulnerable group of patients at a time of limited opportunities. Methods. The project ran from June to December 2022 and involved collaboration of the NGO “Lights of Spirit”, doctors, and specialists including a lawyer, a psychologist, a social worker, and teacher. This multidisciplinary team worked together to provide comprehensive assistance to families with children having SB. Results. Overall, 149 families with children with SB and hydrocephalus from nearly all regions of Ukraine participated in the project. Initially, 82 online consultations were conducted. Nineteen online meetings were organized for parents with the involvement of a physical therapist, an occupational therapist, and a psychologist and 87 families took part in these meetings. Parents and children with SB received online consultations from doctors of the multidisciplinary team, as well as examination, treatment, necessary care products, and medicine tailored to their individual needs. The project also provided educational, informational, and psychological support. Conclusions. The program of multidisciplinary online support of children with SB in Ukraine during the Russian invasion confirmed its significance, necessity, and effectiveness. It facilitated the formation of partnerships between patients, parents, and clinicians. The project showed the problems of prevention and care of children with SB and also prospects for future development in this field.

Keywords: spina bifida; war; support; multidisciplinary team

Introduction

The Russian invasion in Ukraine has huge impact on the health and healthcare system [1]. Many hospitals and vital health infrastructure have been destroyed [2, 3]. More than 450 children were killed and about 900 were injured since the beginning of the full-scale war. Children, especially those with disabilities, are most vulnerable during military conflicts [2]. Patients with spina bifida (SB) have complex multisystem problems related to health and need life-long management by the multidisciplinary team [4].

The war against Ukraine exacerbated the problems of children with spina bifida. Access to healthcare is severely impacted due to security concerns, restricted mobility, and mass displacement [5]. Moreover, part of the population ended up on the occupied territories or territories close to the combat zones, where hospitals are either destroyed or not functioning. Those people are suffering from limited or no access to healthcare and medical supplies [5]. Internally or externally displaced people are also not always able to immediately find appropriate medical support and suffer from the lack of access to medical care. The situation in other regions is not much better. Children and their parents are constantly under the threat of rocket attacks. The way to shelters for children with disabilities and their parents is a real challenge, as elevators do not work during air raid alert, so children and their families are often forced to stay in their homes during it, risking their lives. Those children who can go down to bomb shelters and basements are forced to stay...
there for a long time, which is also reflected on their health. Poor sanitary conditions make it difficult to carry out clean intermittent catheterization and other necessary manipulations. The situation has worsened even more since October 2022, when the aggressor country began to strike Ukraine’s energy infrastructure, which led to massive, forced blackout and, therefore, limited opportunities for development and rehabilitation. All this, of course, is reflected on the psychological state of children and their families [6, 7]. Occupation or resettlement, the lack of access to medical care, missile strikes, air raid alert, and the lack of electricity and heat are far from all the factors that have affected vulnerable groups of the population and children with spina bifida. The horror of war affects the physical and mental health of both children and their parents.

To support children with SB and their parents in the difficult time of war and to improve access to medical care, we have launched a project “The program of multidisciplinary online support of children with spina bifida in Ukraine”. It received support from Child-Help International (Belgium).

The main aim of this project was to support and assist patients with SB and their families, provide consultation with doctors of the multidisciplinary team, examination and treatment, send care products and medicines according to individual needs, ensure informational and psychological support.

Materials and methods

From June to December 2022, the program involved the cooperation of the NGO “Lights of Spirit”, doctors, and specialists (a lawyer, a psychologist, a social worker, a teacher) for optimal many-sided assistance to families with children with SB.

Doctors from the multidisciplinary team were involved in the project: a pediatrician-coordinator, a neurosurgeon, an urologist, a gastroenterologist, an orthopedist, and a rehabilitation specialist.

Parents received information about the project from the head of the patient organization “Lights of Spirit” in the parent group. At the first stage, parents of children with SB filled out a questionnaire to participate in the project. The questionnaire contained basic characteristics of the patient (date of birth, place of residence, whether the family is internally or externally displaced, weight and height of the child). The next section of the questionnaire is related to the data on the child’s health: diagnosis, presence and severity of paraseis, of skeletal deformities, movement ability, past surgical interventions; a list of performed diagnostic examinations (neurosonography, magnetic resonance imaging, electroencephalography, electromyography, ultrasound of kidneys and bladder, urodynamic examination, other special examinations). The parents also indicated the presence of concomitant diseases and complications (hydrocephalus, epilepsy, tethered spinal cord syndrome, neurogenic bladder, urinary tract infections, constipation, fecal incontinence, chronic wounds and bedsores, allergies, etc.). The next section of the questionnaire included data on continuous care: clean intermittent catheterization (CIC), its frequency, and duration; implementation of bowel cleansing technique, its frequency and the use of medical treatment: oxybutynin or other cholinolytics, urinary antiseptics, wound treatment, etc. In a separate section, parents indicated what care products they use: catheter type, size, bowel cleansing systems, hygiene products, diapers, urological pads, etc., and their necessity.

At the second stage, online consultations were conducted with the participation of the coordinator of the multidisciplinary team and the head of the NGO “Lights of Spirit”. Prior written informed consent was obtained from all patients and/or their parents. With their consent, before the consultation, the parents provided case records from the medical history and the results of examinations for deeper familiarization with the medical history. During the consultation, the child’s state of health was evaluated, physical development was assessed, the necessary examinations and problems of continuous care were determined, the vaccine history was studied, as well as the child’s needs for further examinations and specialist consultations were determined, the necessary recommendations were given regarding continuous care, vaccinations. The necessary individual needs for catheters, irrigation systems, medicine, etc. were determined too. With the consent of the parents, final-year students of the medical university were periodically present at the consultations, which was of great importance for raising their awareness of the problem of spina bifida.

At the next stage, depending on the child’s needs, consultations were organized with other members of the multidisciplinary team: a neurosurgeon, a gastroenterologist, an orthopedist, a urologist, a psychologist, and a rehabilitation doctor. If possible and necessary, children were referred to specialists at their place of residence and for additional examination (urinalysis, biochemical blood analysis, ultrasound of kidneys and bladder, brain and spinal cord magnetic resonance imaging, urodynamic testing, etc.).

In addition, group online webinars were held with a physical therapist, an occupational therapist, and a psychologist. If necessary, individual consultations were held with these specialists.

The patient organization sent parcels to different regions of Ukraine with the necessary goods for continuous individual care, which were received from Child-Help International and other charitable organizations.

The study was performed following the principles of the WMA Declaration of Helsinki 1975 (revised in 2000), it was approved by the I. Horbachevsky Ternopil National Medical University Ethics Committee. An informed consent was obtained from the parents of all study participants.

The other objective of this project was raising the awareness of the medical community, medical students, and society about ways to prevent congenital neural tube defects, treatment, and a multidisciplinary approach to medical and social support for children with spina bifida. For this reason, and for the spreading of better care and prevention practices, information booklets were designed and distributed among doctors, pregnant women, and the public. A student conference was held to mark World Spina Bifida and Hydrocephalus Day, covering all aspects of care, management, and prevention of the disease. In addition, students distributed educational materials in medical institutions among pregnant women and young women who plan to become pregnant.
Results

A total of 149 parents of children with SB and hydrocephalus from almost all regions of Ukraine agreed to participate in the project and filled out the questionnaire. This made it possible to create a registry of children with SB and hydrocephalus. Children from only 2 regions (Chernivtsi and Zaporizhzhia) did not participate in the project. Almost half of the children (72, or 48.3 %) were from Western Ukraine. There were 94 female and 55 male patients. The age of the patients ranged from 1 month to 18 years, and the average age was 10.0 ± 5.5 years.

Among the project participants, 118 families remained to live in Ukraine, 20 (13.4 %) moved abroad, and 11 families (7.4 %) were internally displaced to other regions of Ukraine. Among those who left their homes, 27 families (87.1 %) were from regions that were under occupation or from frontline areas. Most families moved to Poland (7), and some — to Italy, Czech Republic, Switzerland, Bulgaria, Serbia, Germany, Lithuania, and Belgium.

Physician’s consultation

Firstly, 82 initial online consultations were held with a pediatrician — a coordinator of the multidisciplinary team and the head of the NGO. Among them, 32 children were referred to and consulted online by a gastroenterologist (Table 1).

The head of the NGO organized consultations and directly participated in them with the consent of parents and doctors, which made it possible to comprehensively solve issues, organize further consultations, and delivery of necessary care products.

Consultations were provided in Zoom; parents and children received information about medical and social issues without leaving home. The duration of the consultation for each patient was approximately 1 hour. Since mid-July, we have been conducting on average 5 online consultations per week. Advice on CIC and bowel cleansing, and information on correcting their technique was provided; educational videos were sent if necessary. We emphasized the importance of children’s socialization (preschool, school, higher education), self-care, independence, the comfort of children’s socialization (preschool, school, higher education), self-care, independence, the comfort of children, and state social guarantees. At the end of the online consultation, parents received a doctor’s report and recommendations for further treatment.

Thanks to the cooperation of the NGO “Lights of Spirit” and Spina Poland Foundation, six families from Ukraine that were forced to leave the country after the Russian aggression, were able to receive multidisciplinary consultations in Katowice. Those were mostly children from the regions that were the first to suffer from the Russian aggression and were under temporary occupation or from the frontline regions. Families abroad received consultations from doctors and patient organizations, underwent examinations and treatment in medical institutions. In other countries, children also had the opportunity to receive consultations, and if necessary, surgical interventions and medical correction were carried out.

Educational and informational support

Nineteen online meetings for parents were organized and held with the participation of a physical therapist (5), an occupational therapist (4), and a psychologist (10), during which parents were able to receive educational information, answers to questions that concern parents in the process of care, treatment, education and leisure of children with SB.

Overall, 87 families took part in these meetings. On average, 25–30 families participated in each meeting. All webinars, which contained general information, were recorded and are freely available on the website of the patient organization “Lights of Spirit” (http://surl.likidzlt). Some families watched video recordings of the webinars after they were held.

Cooperation with the NGO “Active Rehabilitation Group” (Kyiv) was also established and informative online meetings for parents about active rehabilitation camps for children in Poland were held.

Communication of parents during online meetings, in the parent chat, allows them to exchange experiences, better understand the features of continuous care, the use of CIC, the need to involve children in educational activities and leisure; perceive the child’s disability not as a tragedy, but rather different living conditions and promote the independence of children with SB, believe in their own strength and move forward despite all the complexity of the circumstances caused by the war and personal condition.

Parents received information about the correct position of the child’s body, movements, types of wheelchairs, orthoses, features of daily physical activities, prevention of spinal and lower limb deformities, avoiding mistakes in daily care; the peculiarities of the occupational therapists’ work with the child and family, self-care and hygiene skills, everyday and leisure activities, organization of the environment and social skills; stress and depression associated with the birth of a child with spina bifida, perception of the child’s disability, techniques and ways to overcome stress, finding reserves and restoring faith and strength, establishing interaction in the family. Meetings of the NGO members were devoted to the program of support for children with SB during the war (directions of work, responsible people), exchange of parents’ experiences regarding treatment, rehabilitation, and upbringing of children with SB.

Table 1. Consultations provided by doctors involved in the project

<table>
<thead>
<tr>
<th>Specialist</th>
<th>Online</th>
<th>On-site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician, a coordinator of multidisciplinary team</td>
<td>82</td>
<td>7</td>
<td>89</td>
</tr>
<tr>
<td>Neurosurgeon</td>
<td>6</td>
<td>11</td>
<td>17</td>
</tr>
<tr>
<td>Gastroenterologist</td>
<td>32</td>
<td>7</td>
<td>39</td>
</tr>
<tr>
<td>Urologist</td>
<td>–</td>
<td>25</td>
<td>25</td>
</tr>
</tbody>
</table>
Moreover, informational materials on multidisciplinary care, vaccination, prevention of neural tube defects, CIC, bowel cleansing, physical rehabilitation, and socialization of children with spina bifida were created and have been distributed among parents.

In addition to doctors’ consultations and conducting webinars, informational, educational, and advisory support was provided by the head of the NGO “Lights of Spirit” through other means of communication: telephone consultations, Viber chat, and Facebook chat. Every day, there were about 4–5 requests. In general, all 1,495 families who filled out questionnaires and agreed to participate in the program received informational support.

Patients in Poland had the opportunity to participate in the annual SB conference in Poland. Informational support regarding contacts of doctors and SB associations and opportunities for receiving social assistance was also provided for families who were abroad.

**Care products and medication support**

There were formed and sent 380 addressed shipments across Ukraine for 124 families according to the parents’ requests. Patients received catheters, diapers, underpad sheets, wet wipes, vitamin D₃, urinary antiseptics, antiseptic (chlorhexidine), and plasters for wounds. The aid package included donated Child-Help International products, help from a local charitable organization, as well as the purchase of medicine and certain types of care products with the funds provided by the project.

Magnetic resonance imaging of the head and back were conducted for 6 children free of charge (paid by the NGO “Lights of Spirit”). In total, 120 children received New Year’s gifts paid by funds.

**Other activities**

We shared the information about the program of multidisciplinary online support for children with SB in mass media through publications in newspapers and on FB.

We sent letters of appeal to the state institutions of the Ministry of Health of Ukraine, and deputies of the Verkhovna Rada, National Health Service regarding the representation of the interests of patients with spina bifida and provision of catheters for children with SB.

Information about the project “The program of multidisciplinary online support of children with spina bifida in Ukraine”, and its goals were presented by the head of the NGO “Lights of Spirit” at the 29th International Conference on Spina Bifida and Hydrocephalus — “Diverse Needs, Same Rights”, organized by the International Federation for Spina Bifida and Hydrocephalus on September 6, 2022, in Brussels, Belgium online.

Directions of assistance to families caring for children with spina bifida in Ukraine during the war were presented at the webinar “Helping Ukrainians with rare diseases during the war: a clinical perspective” organized by EURORDIS and NCSH “Okhmatdyt” and held in Kyiv, Ukraine on November 18, 2022 online.

We established cooperation with other patients’ organizations in Ukraine and abroad. Since the beginning of Russia’s full-scale invasion of Ukraine, the NGO “Lights of Spirit” has received many offers of support from SB patients’ associations in various countries, including Slovakia, Czech Republic, Germany, Bulgaria, Portugal, Ireland, Great Britain, Lithuania, and the United States. The contacts of the leaders of the associations were given to the parents who were evacuated from Ukraine, which made it possible to receive help in a foreign country timely.

The support of the Ukrainian public and patients’ organizations was also important. In particular, the NGO “Active Rehabilitation Group” (Kyiv) in addition to informational assistance provided children with spina bifida with the necessary incontinence sets and rehabilitation tools. Public union “Orphan Diseases of Ukraine” (Kyiv) contributed to the search for necessary medicine for children with spina bifida.

**Feedback**

The survey conducted after the completion of the project showed the necessity and importance of its implementation. Feedbacks were provided by 94 project participants.

After the consultations, 12 more children (12.8 %) started clean intermittent catheterization and 21 children (22.3 %) started bowel cleansing, which has affected their quality of life. All parents indicated the need for further consultations, educational activities, and communication between parents.

**Discussion**

Besides the direct consequences of the war regarding the life and health of children (death and injuries), the chronic effects of armed conflict affect the physical, psychological, and developmental well-being of children [8]. Violation of access to education, inadequate access to healthcare services, the lack of safe housing, and constant fear of rocket attacks and threats to life increase stress and insecurity in vulnerable groups of children, especially those with disabilities [8, 9].

Thanks to the initiative project, parents and children with SB received attention to their needs, the opportunity to communicate in the parent chat, report their requests and receive quick answers and support according to their needs. Overall, 117 families from almost all regions of Ukraine received online or phone consultations regarding examination, treatment, and rehabilitation of children with SB, informational, educational, legal, and psychological support. Recommendations of various doctors (pediatrician, gastroenterologist, neurosurgeon) were given regarding continuous care (CIC, bowel cleansing, use of oxybutynin, the need for consultations with other specialists, examination, and treatment) and recommendations of the head of the NGO — regarding the socialization and integration of children. Thanks to the project, connections with patient organizations from Poland and other countries were established, and displaced families were able to receive the necessary consultations and assistance.

It was very important that the patients and their families were united in a group and felt daily support, which is very important during wartime when there is a limited access to medical care. Disability is a risk factor for elevated stress-related symptomatology, so it was very significant to provide services for reducing the level of distress among patients and their families [9].
An important aspect of the project was raising the awareness of the medical community and the public about the problems of children with SB and its prevention [4, 10, 11]. An increase in awareness among students and doctors has shown its effectiveness in improving diagnosis and providing assistance in other diseases [12, 13]. We conducted an informational and educational campaign for parents on the prevention of birth defects, multidisciplinary care, and socialization of children with SB. The campaign included a series of webinars, an educational movie, an international conference, online meetings with specialists, and online consultations with doctors. Special attention during consultations was paid to the need to develop the skills of self-management [14], considering all the risks of the war.

An important positive point was that after consultations and communication with other parents, 12.8 % of children started CIC, and 22.3 % started bowel cleansing. These components of continuous care are an important aspect of preserving children in children with spina bifida and prolonging their lives [4, 10].

Unfortunately, rocket attacks on the energy system of Ukraine since October 2022 have led to frequent blackouts, which made regular consultations impossible. Since November, the situation with electricity and the Internet has been very difficult in Ukraine. Considering these circumstances, we had to cancel planned events. Online consultations with the participation of doctors were transferred to telephone or chat mode. Even though only a small part of children with SB in Ukraine was involved in the project, the program aimed at supporting children with SB during the difficult time of war is of great significance both for children and their families, considering the overall global trends in the birth of children with neural tube defects [10]. Thanks to the support of the international community, Child-Help International, and other benefactors, children received not only informational and psychological assistance, but also medical consultations from the multidisciplinary team. Despite facing challenges such as the lack of light, frequent rocket attacks, and air raid alert, which forced to change the time of consultations, most planned activities were successfully implemented.

We hope that this project and international support will be an incentive for the development of multidisciplinary care for children with SB throughout Ukraine, will unite parents and doctors, draw the attention of healthcare providers to the problems of these children, which will ultimately contribute to improving the quality of their lives, despite difficult circumstances. The project made it possible to identify new prospects for the development of preventive measures and multidisciplinary care of children with spina bifida.

Conclusions

Issues of support of vulnerable groups of children are particularly important during military conflicts. The program of multidisciplinary online support for children with spina bifida in Ukraine during the Russian invasion confirmed its importance, necessity, and effectiveness. Thanks to the initiated project, parents and children with SB received online consultation with doctors of the multidisciplinary team, examination and treatment, care products and medicines according to individual needs, educational, informational, and psychological support. The project also contributed to the development of partnerships between patients, parents, and clinicians. The project showed the problems of prevention and care of children with spina bifida and prospects for further development.

References


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Програма мультдисциплінарної онлайн-підтримки дітей зі spina bifida в Україні під час війни

Резюме. Актуальність. Російська агресія проти України загострила проблеми дітей зі spina bifida (SB). Доступ до медичної допомоги погіршився через проблеми безпеки, обмеження мобільності та переміщення. Щоб підтримати дітей зі SB та їхніх батьків у важкий час війни та покращити доступ до медичної допомоги, ми ініціювали проєкт «Програма мультдисциплінарного онлайн-підтримки дітей зі spina bifida в Україні».

Мета нашої роботи: представити програму мультдисциплінарної онлайн-підтримки хворих зі SB та їхніх сімей під час війни для покращення надання допомоги цій вразливій групі пацієнтів у час обмежених можливостей.

Методи. З червня по грудень 2022 року програма передбачала співпрацю ГО «Сяйво духу», лікарів та спеціалістів (юриста, психолога, соціального працівника, педагога) для оптимальної різноманітної допомоги сім'ям зі SB. До проєкту були залучені лікарі мультдисциплінарної команди.

Результати. Загалом у проєкті взяли участь 149 сімей із дітьми, хворими на SB та гідроцефалію, майже з усіх регіонів України. На першому етапі було проведено 82 первинні онлайн-консультації. Організовано та проведено 19 онлайн-застосунок для батьків із залученням фізичного терапевта, ерго-терапевта, психолога, у яких взяли участь 87 сімей. Батьки та діти зі SB отримали онлайн-консультації лікарів мультдисциплінарної команди, обстеження та лікування, засоби догляду та ліки відповідно до індивідуальних потреб, освіту, інформаційну та психологічну підтримку.

Висновки. Програма мультдисциплінарної онлайн-підтримки дітей зі spina bifida в Україні під час російського вторгнення підтвердила свою важливість, необхідність й ефективність та сприяла розвитку партнерства між пацієнтами, батьками і клінічними центрами. Проєкт показав проблеми профілактики й догляду за дітьми зі SB та перспективи подальшого розвитку.

Ключові слова: spina bifida; війна; підтримка; мультдисциплінарна команда