

“Ukrainian SMA registry: assessing the impact of the war on a rare disease community”

Keywords: spinal muscular atrophy, rare disease registries, CSMA, SMA Europe, war, russian invasion, Ukraine

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“Children with SMA” (CSMA) is a non-governmental patient-driven foundation in Ukraine, founded by parents of children with spinal muscular atrophy (SMA). We are dedicated to improving the quality of life of people living with SMA in Ukraine and to support scientific developments in the field.

Introduction

Before the war, people living with rare diseases in Ukraine faced many challenges, and access to specialized medicines and treatment was generally difficult and not prioritized by the government. However, the current war has impacted the lives of people living with rare diseases immensely and their situation has become critical. The military hostilities have created chaos and affected Ukraine’s infrastructure. The Ukrainian medical system has now shifted toward providing primarily military care and the huge migration of Ukrainian residents towards neighboring European countries has added even more pressure to the already vulnerable medical system. Therefore, on top of the struggle to access specialized treatment and care, people living with rare diseases are now also struggling to have access to basic life necessities, which directly threatens their survival.

The everyday challenges that are faced in society in terms of discrimination, stigma, exclusion, financial strain, access to appropriate treatment and care, education, recreation, or employment,

have been aggravated significantly since the start of the war and with the added threat on their survival, many rare disease families are now forced to decide whether they will stay in Ukraine, or risk the dangerous journey to reach safer grounds. In this study, we investigate how (families of) individuals living with SMA are deciding on this difficult question.

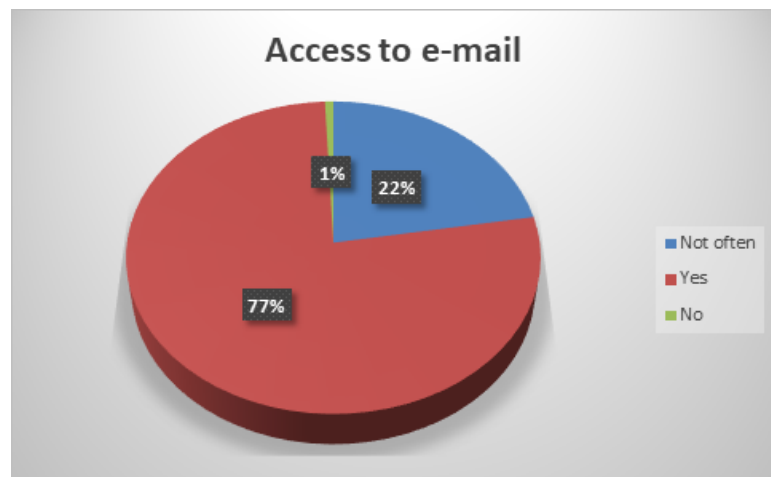


Method

The war started in the early hours of the 24th of February 2022 when Russia attacked Ukrainian cities with missiles. Shortly after, the first families started evacuating out of the attacked areas. To investigate the extent to which SMA families evacuated, a survey was conducted. The survey was emailed to the SMA families through the Ukrainian SMA registry's mailing list, it was posted on the website of the CSMA Foundation, and on social media. The survey was completed by 150 Ukrainian SMA families, which makes up approximately 45% of the total Ukrainian SMA population (both living in and outside of Ukraine) that is known by the foundation. While this is a very high response rate under the current circumstances, it was likely affected by the fact that many families who were still in Ukraine at the time, had no or limited access to the internet (see Figure 1.).

Results

We first asked the families about their access to internet and email. Of all participants who responded, 23% indicated having no or limited access (Figure 1). This finding could potentially mean that many of the families who didn't respond to the survey didn't have access at all to the internet and are thus under our radar.

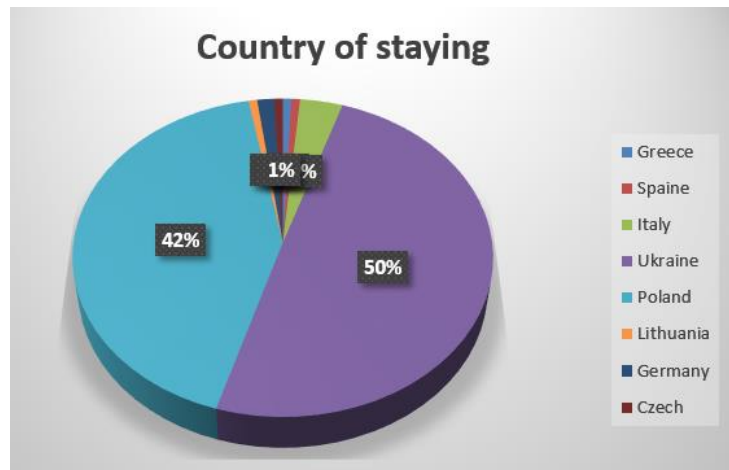


We next asked whether families were currently in Ukraine, or whether they had moved away. Half of the families reported being currently in Ukraine, whereas the other half reported being in a different country (Figure 2.). Of these families, 20% reported having moved away before the 24th of February. This means that 30% of all respondents moved away after the start of the war.

Next, we asked families who were abroad at the time of the survey, when they exactly left the country. There appeared to be a few peaks (Figure 3.): on the 28th of February, the 1st of March and 7th - 8th of March (9 and 10 patients/families). The four days of delay from the start of the war (24th of February) to the first peak on the 28th of February can be explained by the overloaded roads and transportation infrastructure. The next peak reflects patients and families crossing the border from parts of Ukraine that are farther away from the border.



Finally, we asked the SMA families where they crossed the Ukrainian border, where they are currently staying, and where they plan to go in the future. As Figure 4 shows, of the families who moved out of Ukraine after the start of the war.



Analysis of first country of entrance (or staying in Ukraine) shown on Fig.5. A huge amount of stayed patients in Poland reflects not only most popular cross border but suitable conditions and level of help after relocating. It shows how many people uses countries border, and it is in comparison of whole previous period - huge percentage for a couple weeks in comparison years 72% first crossed the border to Poland, and a smaller number moved to the two other neighboring countries of Hungary and Moldova. Furthermore, 68% of all those who left Ukraine are staying in Poland.

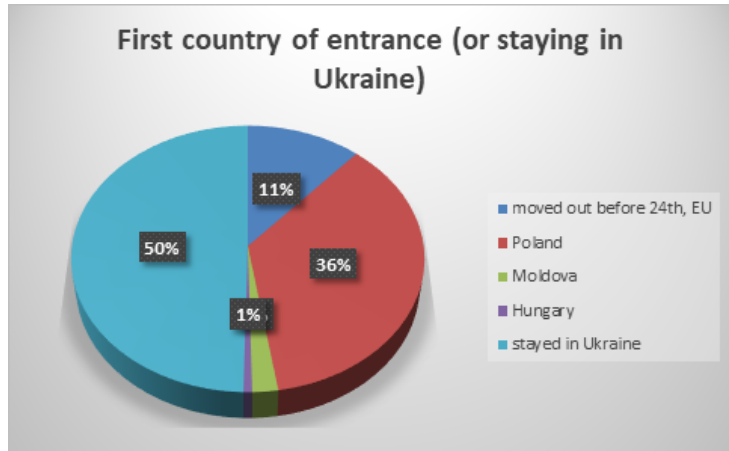
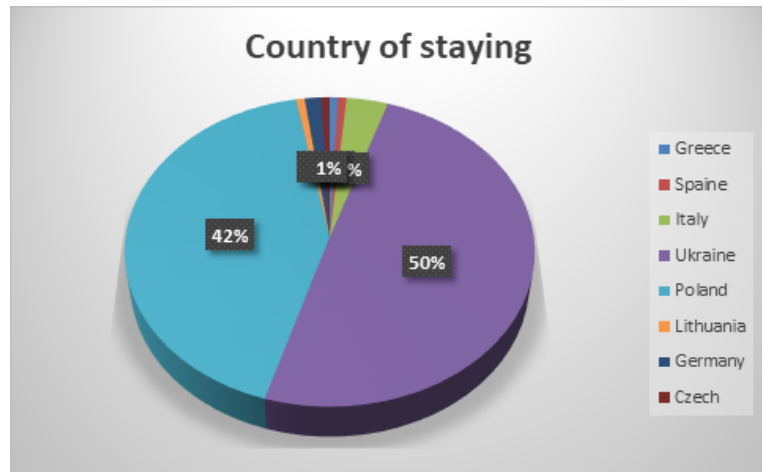


Figure 6. shows, that half or respondents leave Ukraine and a most of half of them leaved after start of the war.



Finally, when asked about their future plans Fig. 7, 83% of the participants responded that they are planning to stay where they are (no plans now), whereas 11% responded that they are planning to move to Poland (from Ukraine) in addition who did not do it already.

While some respondents indicated that they plan to move to a different European country, this was a very small proportion. Together, these findings thus show that a large proportion of the families are currently either living in Poland and are planning to stay there, or they are planning to move there in the future. This indicates that Poland is not only most popular border crossing but also that the conditions of living and the help available after relocation is very suitable for Ukrainian SMA families.



Conclusion

The Russian invasion of Ukraine has led to many challenges and life-threatening situations for individuals living with rare diseases such as SMA in Ukraine. This study shows that half of the Ukrainian patient community is currently living outside of Ukraine. However, this could be an overestimation, as the survey also revealed that families have difficulties accessing the internet. It is thus unclear how many of the patients who didn't respond to the survey are currently trapped without access to the outside world. Unfortunately, this is not specific to SMA, it is similar across the Ukrainian rare disease community.

For the families who have left Ukraine or who stayed in Ukraine but completed the survey, the role of the global disease specific patient community has been invaluable. Many families responded to the survey with requests for help, and they were able to receive first-aid support through the global SMA network. This adds to the importance of having disease specific registries. CSMA is grateful for parents taking part in the Ukrainian Registry. On behalf of all Ukrainian families with SMA we are grateful for the countries who are currently hosting our families. Additionally, we would like to thank SMA Europe and Fundacja SMA (the Polish SMA foundation) for their support since the start of the war.