

13th European Narcolepsy Days, 19th/20th of November '22 in Bologna

Leading up to the congress, eNAP send out a very short survey to the patients in Europe. Thanks to the effort of the organizations on national level we had *almost* 700 reactions in 4 weeks! In Bologna, we asked the professionals who attended the congress the same questions and we compared their answers with those of the patients. The aim was to find out whether professionals and patients are on the same page.

We had 695 responses from different countries (fig. 1) and responses from patients with narcolepsy type 1, type 2 and idiopathic hypersomnia (fig. 2)

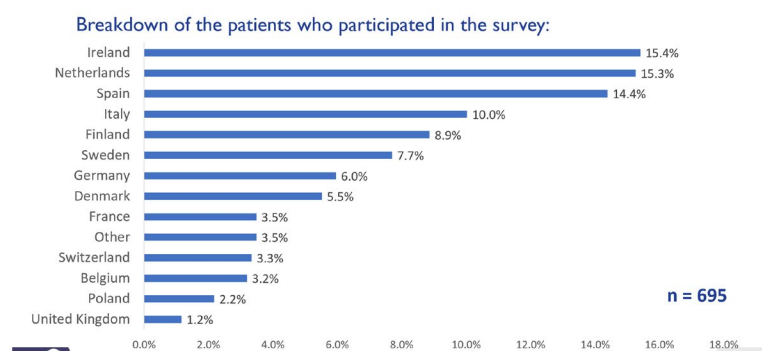


Figure 1

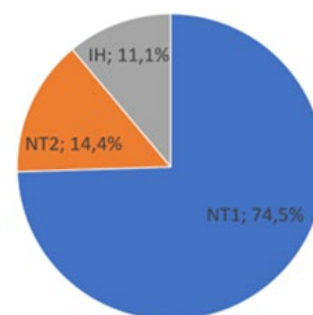


Figure 2

Apart from the 695 responses that we did receive, a major take away is that an even greater response rate is possible, as there was a low reply rate from some countries with large populations. We believe that could be due to the short turn around time of the survey.

We also broke down the patients by gender and age (fig. 3 & 4). It is very typical that more women than men respond to feedback requests. But saying that we would prefer a more representational view of the male experience with narcolepsy and IH.

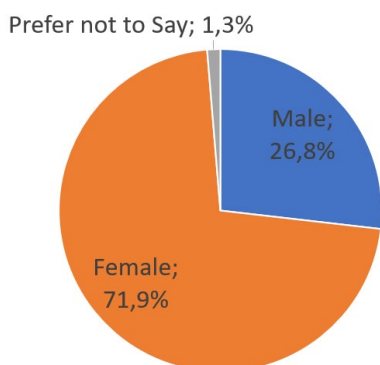


Figure 3

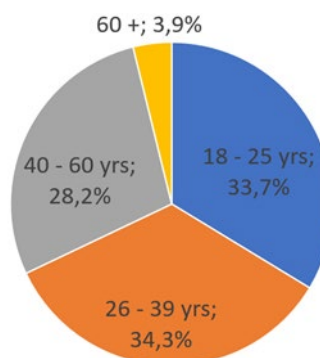


Figure 4

The breakdown of the audience at the congress is shown in fig. 5 - 8. Here we received 99 responses.

Specialists:

Breakdown of the professionals who participated in the survey:

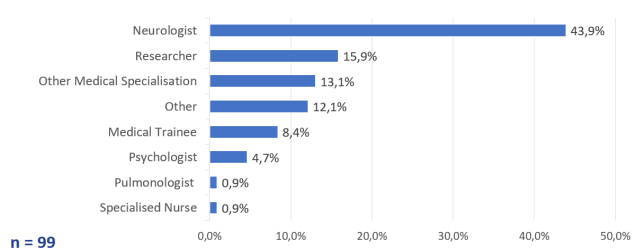


Figure 5

Breakdown of the professionals who participated in the survey:

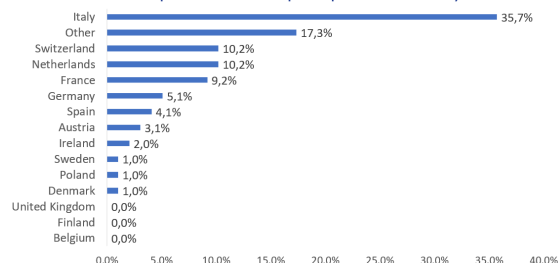


Figure 6

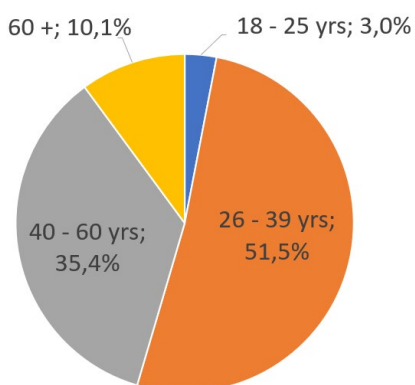


Figure 7

Prefer not to Say; 1,0%

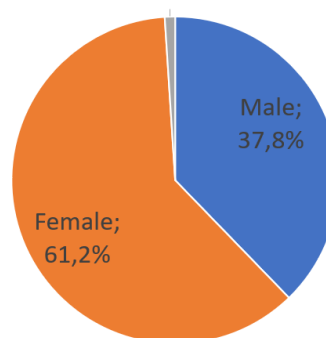


Figure 8

With the demographics over, the following questions deal with how people experience/view narcolepsy and IH, and have/want/need to treat their disorders. These are compared with how the audience thought about the same questions.

What do you consider to be the worst symptoms of having N/IH?

The information shown in the following graph combines the 'what is the worst, second worse and third worse symptoms' questions into one by using weighted averages. We multiplied the number of votes for the worst symptom by 15, the second by 10 and the third by 5 to achieve this.

The first thing to note here is that the order of worst symptoms, as categorized by the patients and professionals, is the same (fig. 9). With that said, further analysis of the data is needed, in that cataplexy is only a symptom for 74.5% of the respondents. It will be interesting to calculate within the NT1 population whether it moves from third to second worse symptom.

It seems that the professionals have over-estimated the impact of lack of concentration/brain fog and under-estimated the impact that an interrupted night sleep has, in comparison to the patients.

Please, bear in mind that this was not a scientific survey and we have not calculated confidence levels to evaluate whether the differences are significant.

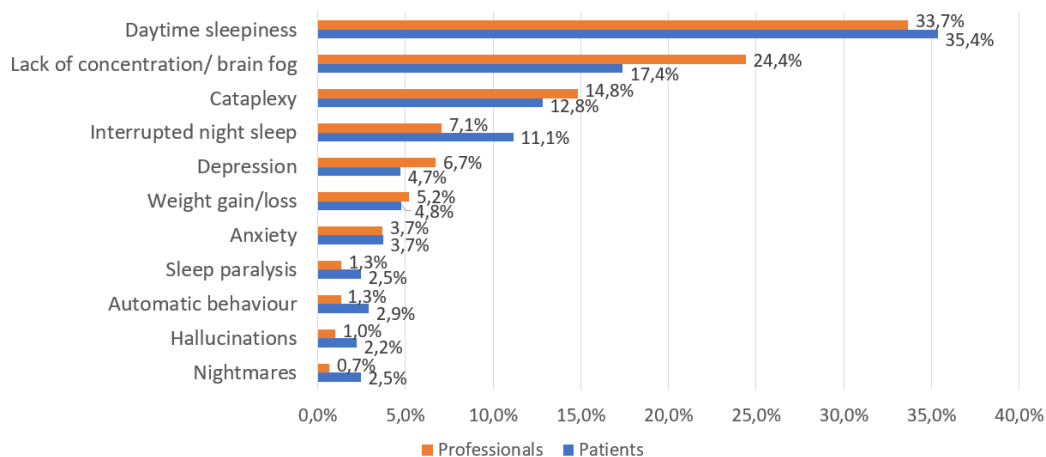


Figure 9

To what degree does N/IH have an impact on the following aspects of life?

Here the patients ranked work/education; isolation/social life; and hobby/sports as the top areas of the life that has been impacted (fig. 10). Interestingly, the professionals expected self esteem to be more impacted.

This does give some insight into areas where the patient organisations can possibly focus on to help the patients in their countries. One might even connect the lack of hobbies and sport as being a strong factor in the high levels of isolation/lack of social life experienced.

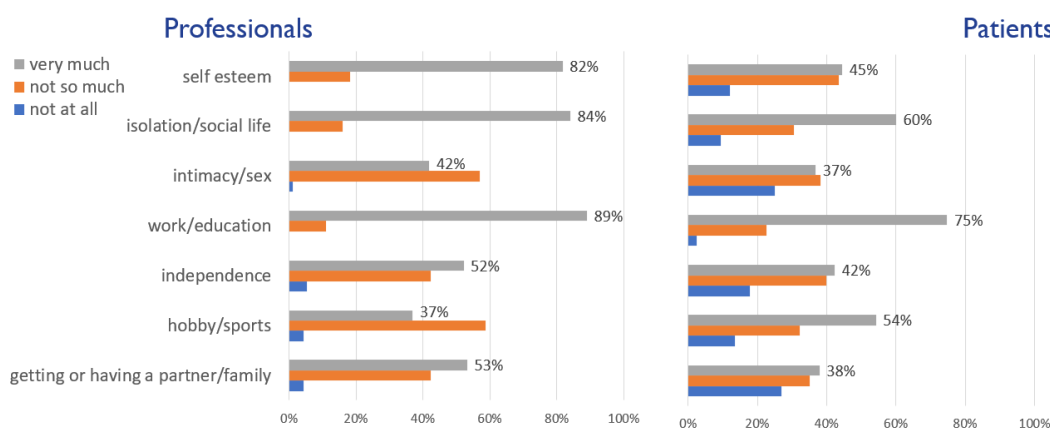


Figure 10

What professional assistance helps in living with N/IH?

Access to neurologists/medication is high which was expected.

Access to the other arms of a multi-disciplinary approach to narcolepsy/IH appears to be lacking and greatly over estimated by the professionals (fig. 11). It will be interesting to break this down by countries.

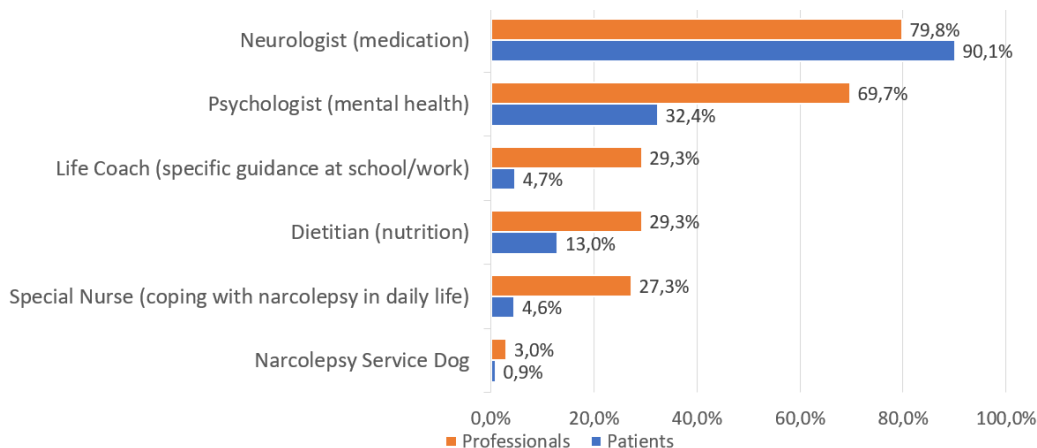


Figure 11

What additional professional assistance do you think could be helpful in living with N/IH?

When asked what could help, 21.6% of the patients stated neurologist/medication. This is why we feel that we should have separated these two elements. Does this mean that the respondents do not have access to a neurologist and are being seen by a different type of doctor, or are that they are not happy with the medication or the availability of medication in their country? We need to take a closer look at that.

Access to a life coach, psychologist, special nurse and dietitian appear to be broadly wanted but unavailable. The desire/interest for narcolepsy service dogs (even without doing any calculations) appears to be very dramatic, keeping in mind that only 0.9% of the respondents actually had a narcolepsy service dog.

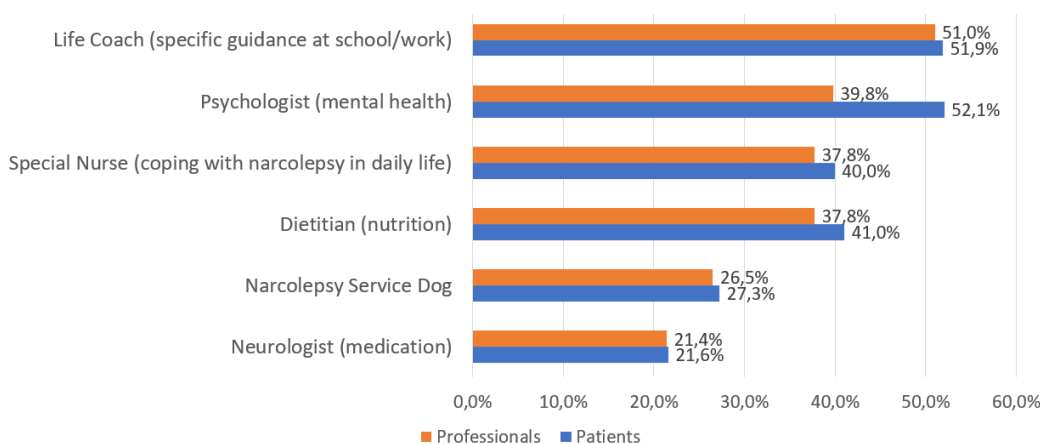


Figure 12

From here, we need to further breakdown the raw data to extract information to help in the design of the large patient survey which we have spoken about before. This will be the first big project for eNAP with the goal of getting a more detailed understanding of what it is like to live with N/IH across Europe.

This short questionnaire was a success in that we discovered that the patients and the professionals who attend the EUNN congress are on the same page. One comment, made at the congress, does need to be kept in mind. Those attending the congress are highly experienced on N/IH. It was questioned what kind of response would we get if the treating doctors around Europe were asked to fill out the questionnaire. Would they have a similar level of overlap with the patients' view?