

# Effectiveness of a digital platform for sharing knowledge on headache management: a two-year experience

Vincenzo Raieli, MD<sup>a</sup>  
Edvige Correnti, MD<sup>b</sup>  
Antonino Sandullo, MD<sup>c</sup>  
Marcello Romano, MD<sup>d</sup>  
Francesca Marchese, MD<sup>b</sup>  
Carmela Loiacono, MD<sup>b</sup>  
Filippo Brighina, PhD<sup>e</sup>

<sup>a</sup> UO NPI- P.O. Cristina - ARNAS Civico Palermo, Italy

<sup>b</sup> Child Neuropsychiatry School, University of Palermo, Italy

<sup>c</sup> Primary Care Dept. -ASP 1 Agrigento, Italy

<sup>d</sup> Neurology Dept.- Cervello, Villa Sofia Ospedali Riuniti, Palermo, Italy

<sup>e</sup> Department of Experimental Biomedicine and Clinical Neurosciences, University of Palermo, Italy

Correspondence to: Vincenzo Raieli  
E-mail: vinzi.raielk@inwind.it

## Summary

**It is crucial that all headache specialists receive adequate training. Considering the unsatisfactory results obtained with standard updating courses and the growing need for continuing professional education, a digital platform was developed as a training tool. The platform has been active since 1 October 2014. It is readily accessible to doctors by free registration. Users have access to all the material available on the platform, which includes scientific articles, e-books, presentations and images. Users can share their own material and clinical cases directly. At the time of this study, the platform had 37 users. In the second year following its launch 316 files were downloaded and five discussions were started. These saw 22 contributions. Fifteen of the 37 members did not perform any action on the platform. In total, 74 files were uploaded in the second year of activity, but 90% of the contributions came from a very small group of users. There were no significant differences in use of the platform between members of the Italian Society for the Study of Headache and other specialists. Even though the platform appears to be an easily accessible, interactive and inexpensive instrument, the higher number of downloads than uploads suggests that it is used passively.**

**KEY WORDS:** digital platform, education, headache, headache training, headache management, migraine.

## Introduction

Headache management, in both pediatric and adult populations, is an extremely challenging area from the perspective of the patient-doctor relationship (Raieli et al., 2010). Furthermore, medical training in this field, provided to primary care physicians, pediatricians and headache specialists, is currently far from optimal. The importance of these issues is not sufficiently appreciated, likely due to an underestimation of the problem by health policy makers (Brighina et al., 2006), and this has a considerable impact on the work of both general practitioners (poor recognition and/or under-treatment of primary headaches, over-reliance on emergency departments, etc.) and specialists (superficial approach to what is a complex disease, reduced adherence to guidelines, poor communication among specialists, etc.) (Brighina et al., 2006). This problem is seen in several industrialized countries, for example 66% of German adolescents with headache have never visited a doctor for their condition (Albers et al., 2015), and in the United States pediatricians send only 7% of patients affected by minor headaches to pediatric neurologists (a smaller percentage compared with the rate of referrals to these specialists for other conditions) (Bale et al., 2009), even though the World Health Organization lists migraine as the seventh most disabling disease, underlining that physicians should pay close attention to patients suffering from headache (WHO, 2011).

For these reasons, in 2006, our group (the Sicily section of Italian Society for the Study of Headache - SISC) started a cooperation project between patients, general practitioners and specialists (Brighina et al., 2006). This experience, confirming recent literature, highlighted the role played by headache specialist in leading the diagnostic-therapeutic process and in the training of general practitioners (Minen et al., 2015, 2016; Ahmed and Faulkner, 2016). An important question to be asked in this regard is whether specialists are sufficiently trained and motivated to drive these processes using the usual tools and channels, such as university studies, scientific societies, journals, the internet, conferences and training courses. The creation of a clinical network focusing on headache should consider primarily the most problematic aspects, such as specialist training in the treatment of headaches. In this regard, the limiting and critical factors include declining interest, among industrial sponsors, in promoting professional development, geographical distances, the lack of time available for training in the workplace, and so on. These factors might explain why, after more than 10 years of work, the problem seems to be far from solved. We have also obtained inconsistent and unsatisfactory results from residential training courses for general practitioners and special-

ists. It is becoming increasingly apparent that there is a need for a continuous and permanent form of training that is readily accessible, interactive, inexpensive and not time consuming. To achieve these goals we developed a tool for continuous learning, exploiting the possibilities offered by an online platform. We here report our experience with this platform two years after its launch as an instrument designed to promote interaction between physicians and specialists interested in the field of headache.

## Materials and methods

With the technological support of an industrial sponsor (Janssen), a digital platform has been active online since 1 October 2014. For the first year the network was devoted exclusively to headache in childhood. At the start of the second year, it was extended to all age groups, allowing specialists on adult headache to join as well. The platform is easily accessible by doctors, requiring only registration (free of charge) and approval from the administrators of the network (VR, FB and AS). During these two years, the administrators repeatedly invited members of the Sicily sections of SISC and of the Italian Society of Child and Adolescent Neuropsychiatry (SINPIA), as well as other potentially interested specialists, to join the network. After their initial registra-

tion and login, users can access the platform resources (articles, books, Powerpoint images, etc.) and also upload new material. They can discuss clinical cases or submit new cases or topics. Users can choose to receive an e-mail notification of every new contribution. We also created a WhatsApp group to alert members to each new contribution and encourage real-time communications. The system allows the administrators to monitor the network members' activity (accesses, resource uploads and/or downloads, submission of clinical cases and participation in discussion of cases).

We also e-mailed a questionnaire (Table I) to all members, in order to better understand why single members were using/not using the platform. Finally, knowing that there also exist platforms on other medical topics supported by the same sponsor, and interested to know more about their use for comparison with our own experience, we requested relevant data from the sponsor.

## Results

On October 1 2016 (exactly two years after its launch), the platform had a total of 37 registered members (n. 29 in the pediatric headache section, n. 22 in the adult section, 14 registered in both sections); 18 of these are SISC Sicily section members (18/55: 27.7%). The resources uploaded on the platform consist of many dif-

Table I - Questionnaire on members' use of the platform in the past year.

Question 1: In monitoring use of the platform over the past year I've observed how many times (few/many/never) you have entered the platform compared to the average by colleagues. What does your behavior depend on? (You can give a maximum of 3 responses, numbering them 1,2,3 in descending order of importance)

1. Difficulty accessing the platform
2. Ease of accessing the platform
3. Right now I have little interest in the topic
4. Right now I am particularly interested in the topic
5. I find the resources very interesting
6. I find the resources uninteresting
7. I am not interested in participating in the discussions
8. I am interested in participating in the discussions, but I don't have time to do so
9. Difficulty downloading the contributions
10. Ease of downloading the contributions
11. I am not receiving the notifications of new contributions
12. I get the notifications of new contributions
13. I haven't found a contribution that interests me
14. I don't have enough time to go on the platform
15. Other (please specify:)

Question 2: What would you like to see added to the platform in order to facilitate your participation?

Question 3: Do you consider it useful to be able discuss your difficult clinical cases of headache with other experts? What might make it difficult to do so?

Question 4: Did you know that there is a WhatsApp group that can alert you in real time about contributions entered or being discussed? Would you join it? If not, why not?

Question 5: What else is needed, in your opinion, to enhance the platform?

Question 6: Do you think that it would be useful to set up a group on Facebook or other social networks? What could this add to what the platform offers?

ferent materials concerning headache: a collection of more than 100 articles on migraine aura, several books and numerous libraries of slides on different headache-related topics, collections of artistic images on migraine, sets of headache-related neuroradiological images, various clinical material for headache monitoring and treatment, such as medical records, diary cards, diet plans, physical exercises, and so on. Finally five clinical cases have been reported and discussed on the platform by members.

Table II provides general data on user participation in the platform during the second 12 months following its launch. The data are divided by the following user categories: members of the two scientific societies (SISC or SINPIA), other medical specialists with an interest in headache disorders.

Monitoring of activity in the second year showed 316 file downloads, whereas 74 files were uploaded (books, articles, collections of articles, sets of neuroradiological images, etc.) mainly by three network members (especially VR), and five clinical cases were submitted and subsequently discussed (22 contributions).

Interestingly, it was found that 15 of the 37 members had never performed any action on the platform. These results indicate that most members use the platform mainly passively, or not at all. Finally, to better understand the reasons for the different patterns of use of the platform by the registered members, we e-mailed a six-item questionnaire to all of them (Table I). Answers were received from 22/37 (59.4%) members and submitted to analytical examination. In response to question n.1, 50% of subjects reported having little time to access the platform (answer n.14); 40.9% claimed they had difficulty accessing it (answer n.1); 31.8% claimed they were interested in participating in the discussions but did not have enough time; 27.7% claimed they found the resources very interesting. With regard to question n. 2, 63.3% believed that the platform works optimally as it is and does not need any changes or updates; as for question n.3, 77.3% agreed that discussion of clinical cases is important, but some members claimed not to have enough time to devote to this; the replies to question n.4 showed that almost all the responders felt the WhatsApp group to be a good idea, and the best way of being alerted; as for question n. 5, most of the responders did not make other suggestions, even though some proposed organizing web conferences or adding videos of headache patients, and increasing the number of clinical

cases uploaded and discussed; finally, in response to question n.6, the majority (54.5%) felt that the creation of a Facebook group would be useful in order to make accessing the information quicker and easier, and to improve communication, while 31.1% did not consider the creation of a Facebook group or a dedicated web page either useful or necessary.

## Discussion

For several years (starting in 2003), the Sicily section of SISC, with the aim of providing correct information on headache, endeavored to promote learning programs aimed at general practitioners, pediatricians, headache specialists and also patients. Despite its considerable efforts (through meetings, courses, repeated invitations to cooperate, and so on), the level of communication, even among specialists, remained poor and discontinuous. In view of this, we felt that the use of a common social network might be a suitable approach for creating a community in which to freely debate clinical cases and add clinical and educational materials. We subsequently decided that a digital platform would be a good tool for continuing education, as it gives more experienced doctors the possibility to upload contributions, and also allows interaction among colleagues, and the sharing of resources of several types. However, the data collected two years after the launch of the platform showed that about 40% of the members had never actively used it, while the remaining 60% mainly used it in a passive way, just downloading the available resources. Indeed, only a few members had uploaded resources or clinical cases or actively participated in discussions. Moreover, in spite of the fact that joining and accessing the platform is free, only a small proportion of Sicilian SISC members responded to the (numerous) invitations to register on it. Furthermore, the rate of downloads was found to be similar between the users from each of the two scientific societies, even though one of these societies has a more general field of interest; indeed members of the other society (SISC), which is specifically devoted to the field of headaches, might in theory have been expected to be more interested in actively using the platform. To better understand this behavior, the subscribers were administered a questionnaire about their use of the platform. The ratio of responders to non-responders was the same as that between active and

Table II - Use of the headache digital platform by different user categories.

Academic groups	Number of users	Number of inactive users (no actions)	Number of logins	Number of file downloads	Number of file uploads	Number of clinical cases submitted	Number of users participating in clinical case discussions
SISC members	18	5	112	146	68	4	20
SINPIA members	11	6	28	139	3	1	2
Other medical specialists	8	4	7	31	3	0	0
Total	37	15	147	316	74	5	22

Abbreviations: SISC= Italian Society for Study of Headache; SINPIA= Italian Society of Child and Adolescent Neuropsychiatry.

passive members (22:15), even though it emerged that some of the responders were passive members (no login action) and some of the non-responders were active members. In brief, the results show, unsurprisingly, that lack of time is the main reason given for non-use of the platform, even though digital instruments theoretically offer potential users more flexibility to choose when to log on and participate (be it for learning purposes or to contribute to discussions of clinical cases). We wondered whether this non-use or passive use of the platform might be dependent on the specific topic dealt with (headache), or whether it was, instead, a feature common to other digital platforms dealing with other diseases. To investigate this aspect, we asked the sponsor for use data on platforms aimed at other specialists. These platforms number 33 in total and the sponsor provided data on some of them. As reported in Table III, we observed that, with the other platforms, too, the rate of active use and downloads was low considering the total number of registered members. The overall finding of our study therefore reflected the data on other platforms dealing with various other specialties: generally only a minority of registered members were found to be active participants.

This finding could be the result of poor attractiveness of the platform, with regard to both its content and the discussions. However, considering that this digital instrument was created specifically to provide an opportunity to interact with many other users, and the network members were repeatedly contacted, via email and WhatsApp, and invited to participate in discussions and make contributions, the lack of feedback would seem to indicate, rather, a lack of real engagement with the issue, even though the network members subscribed voluntarily and, in some cases, were members of a scientific society specifically devoted to the field of headache.

These observations will complement the existing literature, highlighting the difficulties in diagnosing and treating headache, largely due to the insufficient attention paid to the disease in medical degree courses at all levels, including the training of general practitioners and specialists (lack of specific training programs). The importance of headache appears to be underestimated on both an emotional and an intellectual level, even by col-

leagues belonging to scientific societies devoted to the problem (WHO, 2011; Minen et al., 2016). These data confirm that a critical aspect of medical education on the diagnosis and treatment of headaches is the ability of doctors to really engage with this issue on an emotional level. Such engagement, fostered by a real appreciation of and active interest in the headache patient's problem, would also favor the emergence of a more empathetic relationship with these patients, and allow them to benefit from the care of a physician who is genuinely interested in their suffering. This consideration has already been made in studies showing that migraine patients treated by doctors who are themselves affected by migraine feel that they receive a better quality of care (Weber et al., 2002).

In conclusion, these data seem to confirm the importance of emotional involvement in the professional training and continuing education of medical doctors, a factor that seems to count more than the technical efficiency of the training instrument itself, given that the latter, even when readily available and easy to use, is not always readily employed.

It can be hypothesized that making membership of an official headache network mandatory, at least for physicians belonging to specific scientific societies, might, in the context of an explicit duty of care for these patients, lead doctors to become more involved in continuing education in this field, and more willing to support training initiatives of different types.

## References

- Ahmed ZA, Faulkner LR (2016). Headache Education in Adult Neurology Residency: A Survey of program Directors and Chief Residents. *Headache* 56:871-877.
- Albers L, Straube A, Landgraf MN, et al (2015). Migraine and tension type headache in adolescents at grammar school in Germany burden of disease and health care utilization. *J Headache Pain* 16:52.
- Bale JF Jr, Currey M, Firth S, et al (2009). Executive Committee of the Child Neurology Society. The Child Neurology Workforce Study: pediatrician access and satisfaction. *J Pediatr* 154:602-606.

Table III - Use of some other Italian digital platforms by other specialists.

---

Other Italian digital platform to October 2016

JBOARD CLUB COSENZA (PAIN) → members n=10, downloads n=16, active members n=8

JBOARD CLUB ALGOLOGY (PAIN) → members n= 4, downloads n= 6, discussions n=18, active members n=4

JBOARD CLUB VICENZA (GASTROENTEROLOGY) → members n=14, downloads n=23, discussions n=1, active members n=7

JBOARD CLUB CALTANISSETTA (GASTROENTEROLOGY) → members n=35, downloads n=141, discussions n=2, active members n=12

ADVISORY BOARD Multidisciplinary Young Faculty (ONCOLOGY) → members n=22, download n=159, discussions n=5, active members n=20

Network SPDC (PSYCHIATRY) → members n=190, downloads n=32, discussions n=1, active members n=44

---

- Brighina F, Raieli V, La Pagna GF, et al (2006). Disability and social impact of headaches and migraine. The role of information and cooperation among patient, general practitioner and specialist: A project of the SISC Sicilia. *Giornale delle Cefalee* 2:10-12.
- Minen MT, Monteith T, Strauss LD, et al (2015). A New Investigator and Trainee Task Force Survey on the Recruitment and Retention of Headache Specialists. *Headache* 55:1092-101.
- Minen M, Shome A, Halpern A, et al (2016). A migraine management training program for primary care providers: An overview of a survey and pilot study findings, lessons learned, and considerations for further research. *Headache* 56:725-729.
- Raieli V, Compagno A, Puma D, et al (2010). Headache: What do children and mothers expect from pediatricians? *Headache* 50; 2:290-300.
- Weber M, Daurès JP, Fabre N, et al (2002). Influence of general practitioners' personal knowledge on migraine in medical attitudes towards their patients suffering from migraine. *Rev Neurol* 158:439-45.
- World Health Organization and Lifting. The Burden. Atlas of Headache Disorders and Resources in the World 2011. Geneva: WHO; 2011.