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Images depicting headache pain – a tool to aid the diagnosis of cluster headache: a pilot study

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Introduction and objective: The diagnosis of primary headaches is based on the International Classification of Headache Disorders (ICHD-3). Cluster headache (CH), a debilitating primary headache, is often misdiagnosed as migraine. In the absence of biological markers, a new visual screening tool with images depicting pain could aid the correct diagnosis of CH. The objective of the study is to test the tool on healthy participants and participants with CH and migraine.

Methods: In phase 1, 6 images portraying people with pain were tested on 150 healthy participants. The healthy participants were asked to rate the images as mild, moderate, severe or excruciating pain. In phase 2, the images were further tested on 116 participants with headache (16 participants with CH, 100 participants with migraine). The participants were recruited prospectively from a tertiary headache center between February and May 2017. The participants were asked to choose which image best illustrated their headache attacks.

Results: Phase 1 results showed that the images represent a range of headache pain severities from mild to excruciating as rated by healthy participants. They rated two images as excruciating, one image as severe, one image as moderate/severe, one image as moderate and one image as mild. Phase 2 results showed that two-thirds of participants with CH (69%) and half of the participants with migraine (52%) chose an image described as excruciating by the healthy participants.

Conclusion: We developed a screening tool with six drawings depicting headache pain severities from mild to excruciating as rated by the healthy participants. Although the images did not differentiate between CH and migraine, the study indicated the potential of using visual aids to assess headache severity.

Keywords: drawings, migraine, screening tool, diagnosis, visual, pictures, excruciating

Introduction

Headache disorders are the second leading cause of years lived with a disability worldwide and interventions are urgently needed to reduce this burden throughout the world.¹ Cluster headache (CH), a severe primary headache,² is often referred as “suicide headache” because of the suicide rate among CH sufferers.³ Females with CH have described their cluster attacks as worse than childbirth.⁴ Although CH is not a rare condition, with a prevalence (1/1000)⁵ similar to the prevalence of multiple sclerosis (0.9/1000)⁶ and Parkinson’s disease (1–3/1000),⁷ it is not well known across both primary and secondary health care settings and therefore often misdiagnosed.⁸ It is difficult for health professionals who are non-headache specialists to diagnose CH.⁸ The delays in diagnosis and misdiagnosis (and subsequent mistreatment) occurs primarily because CH is

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confused with migraine.^{9,10} Migraine patients describe the headache pain as moderate and severe, during an attack they prefer to lie down in a dark room and avoid physical activity.¹¹ The intensity of migraine attack develops over hours and can last up to three days.^{2,12} In contrast to migraine, the pain intensity of CH is excruciating and is described as one of the most painful conditions known to mankind.¹³ A CH attack starts abruptly and usually ends within three hours, these are associated with severe restlessness during the attacks.⁵ A correct diagnosis is important as CH and migraine are managed differently.¹⁴ CH is treated with high flow oxygen, subcutaneous triptans as abortive medication and verapamil as preventative treatment.¹⁵ Migraine attacks are treated with oral triptans and tricyclic antidepressants, and β -blockers or antiepileptic medication to prevent attacks from occurring.¹⁶

To date, there is only limited research evidence on visual aids during headache¹⁷ or pain consultations.^{18–20} One study explored the usefulness of a visual diagnostic aid for paediatric headaches.¹⁷ Drawings made by children of their headache pain and associated symptoms (eg vomiting, sensitivity to lights, visual aura) were found to be useful to differentiate migraine from non-migraine headache.¹⁷ Other studies found that laminated photographs suggestive of pain could improve the communication during pain consultations.^{18–20} To date, the diagnosis of CH is based on clinical history² and there are no biological markers.²¹ In the absence of such biomarkers, a new visual screening tool with images representing different pain severities could aid health professionals in assessing whether the patient suffers from migraine or CH and decrease common misdiagnosis and delays in diagnosis.

There are two things that lay at the inceptions of this study. Firstly, a small interview study conducted by FA in our research team, in which CH and migraine patients were interviewed and a set of images was used to identify their symptoms and capture their verbal description of pain.²² Secondly, the ARTe Cluster Project, led by Claudio Geraci, that collects and exhibits artistic renditions of CH to raise awareness of the huge impact the disease has on CH sufferers.^{23,24} We developed the visual screening tool with two objectives in mind: (1) to determine if six images depict a range of pain severities from mild to excruciating. This was achieved by asking healthy participants to score the images; (2) to test the visual tool on participants with CH and migraine

to determine which image best represented the pain during their headache attacks.

Methods

Screening tool development

We decided to use a range of images that depict headache pain in different ways, inspired on real life pictures and images frequently used on CH websites.²⁴ The same person sketched six drawings as we wanted all the images to have similar characteristics (color saturation and chromatic range) in order to avoid the influence of color on attentional bias.²⁵ All images were printed in black-and-white on the same size.

Phase 1

The screening tool was tested on 150 healthy participants to determine if the images depict a range of pain severities. These were people without a history of headaches or chronic pain conditions. The healthy participants were asked to rate each image as showing mild, moderate, severe or excruciating pain. They had the option to choose multiple answers or not to answer (Figure 1).

Phase 2

The screening tool was further tested on 116 participants with headache (16 participants with CH, 100 participants with migraine). Participants received a prior diagnosis of CH or migraine (control group) based on the ICHD-3b²⁶ criteria before they were enrolled in the study. The participants were recruited prospectively from a tertiary headache center between February-May 2017. The participants were asked to choose which image best illustrated their headache attacks (Figure 2).

Ethics

This study received ethical approvals from the local University of Hull Research Ethics Committee (1613/27.09.2016) and from the UK Health and Social Care Research Ethics Committee (HSC REC) (16/NI/0269). Written informed consent was obtained from all participants before taking part in the study.

Results

Phase 1

One hundred and fifty healthy participants were included in the study. Our findings are that the participants agreed that the six images in the screening tool are depicting a range of pain severities from mild to excruciating (Table 1 and Figure 3). The participants rated image 1 ($n=131/150$,

Please answer the following questions:

(There is no right or wrong answer. Please rate all the images. You can choose more than one image for each answer but you cannot choose the same image for more than one answer)

Which images/s, in your opinion, represent/s:

1. excruciating pain? _____
2. severe pain? _____
3. moderate pain? _____
4. mild pain? _____



Image 1



Image 2



Image 3



Image 4



Image 5



Image 6

Figure 1 Visual tool tested on healthy participants.

87%) and 5 (n=93/150; 63%) as “excruciating”. Twenty-one percent (n=32/150) of the participants chose not to rate image 5. Therefore, image 1 seems to be more representative for expressing an excruciating level of pain. Image 2 was rated as either moderate (n=60/150; 40%) or severe (n=59/150; 39%). The participants rated image 3 (n=93/150; 62%), image 4 (n=88/150; 58%) and image 6 (n=129/150; 86%) as showing severe, moderate and mild level of pain respectively.

Phase 2

One hundred and sixteen participants were included: 100 participants with migraine (93 participants with chronic migraine; seven participants with episodic migraine) and 16 participants with CH (nine participants with chronic CH; seven participants with episodic CH). Eighty-six percent (86%) of the participants with migraine are females and 14% males with a mean age of 44 (SD 11) (females n=86/100; males n=14/100). Nineteen percent (19%) of

Participant no __
 Male/Female
 Age __
 Diagnosis: Migraine/Cluster Headache; Episodic/Chronic

Please choose one image that best illustrates the most severe headache you have experienced:

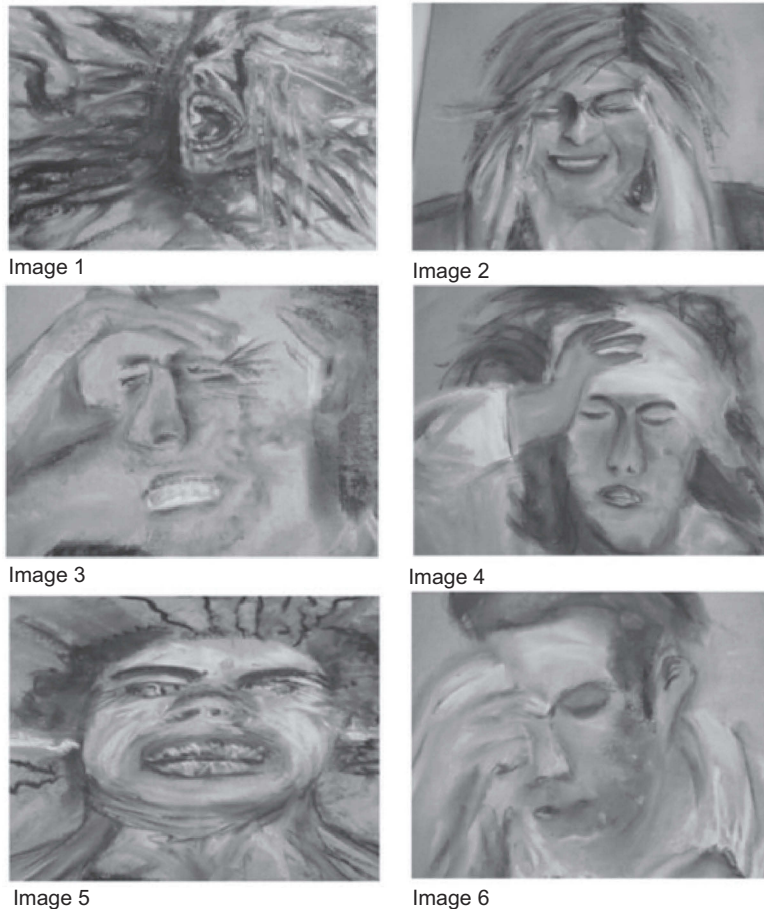


Figure 2 Visual tool tested on participants with cluster headache and migraine.

Table 1 Image rating according to severity

| Image no. | Severity rating (number of participants) | | | | |
|-----------|--|----------|--------|--------------|-----------|
| | Mild | Moderate | Severe | Excruciating | No rating |
| Image 1 | 0 | 0 | 1 | 131 | 18 |
| Image 2 | 9 | 60 | 59 | 4 | 18 |
| Image 3 | 2 | 18 | 93 | 25 | 12 |
| Image 4 | 26 | 88 | 24 | 4 | 8 |
| Image 5 | 0 | 3 | 22 | 93 | 32 |
| Image 6 | 129 | 15 | 1 | 0 | 5 |

participants with CH were females and 81% males with a mean age of 48 (SD 14) (females n=3/16; males n=13/16) (Table 2).

Two-thirds of the participants with CH (n=11/16; 69%) and half of the participants with migraine (n=52/100; 52%) chose image 1 as being the most



Figure 3 Image selection by healthy participants.

Table 2 Demographics of the study population

| Variable | Migraine | Cluster headache |
|----------------------------|----------|------------------|
| Number of participants | 100 | 16 |
| Number of female/male | 86/14 | 3/13 |
| Number of episodic/chronic | 93/7 | 7/9 |
| Gender ratio (female/male) | 6.14 | 0.23 |
| Age in years: mean (SD) | 44 (11) | 48 (14) |

representative for their headache attacks (Figures 4 and 5 and Table 3). Image 2 or image 3 are representative for the attacks of 41% (n=41/100) participants with migraine (and 25% participants with CH; n=4/16). Image 4 was chosen by 4% (n=4/100) of participants with migraine and 6% (n=1/16) of participants with

CH. Image 5 and 6 are representative for the attacks of 3% (n=3/100) of participants with migraine whilst no participants with CH have chosen these two images.

Discussion

Healthy participants determined that the six images in the new screening tool portray a range of pain severities from mild to excruciating. Our findings indicate that two-thirds of the participants with CH chose image 1, rated as excruciating by healthy participants to represent their attacks. This could imply that participants with CH regard their pain as “excruciating”, which is consistent with the current literature.^{4,27} According to the International Classification of Headache Disorders, migraine is described as moderate/

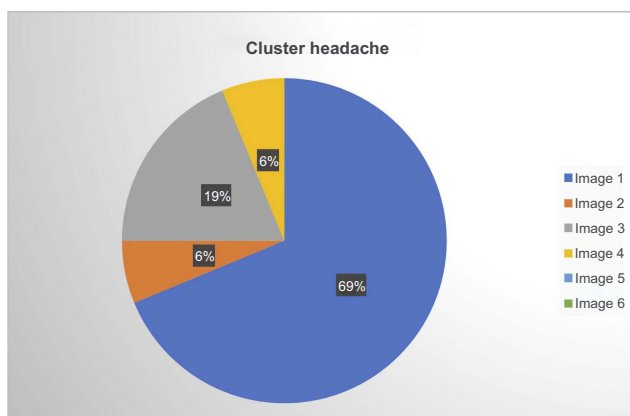


Figure 4 Image selection by participants with cluster headache.

severe pain whereas CH as severe/very severe pain² of excruciating quality.⁴ Furthermore, the intensity of pain is regarded as a key feature in differentiating CH from migraine.² CH is described by female sufferers as worse than childbirth⁴ or as the worst pain one can experience.¹³ Half of the participants with migraine in this study (52%) chose image 1 as representing their attacks. This could indicate that the pain perceived by half of the migraine participants could be interpreted as “excruciating”. However, this was suggested from the image chosen, which was rated by healthy participants. A previous survey study reported on the presence of “excruciating pain” in CH and other primary headaches.²⁸ The “excruciating pain” had a low specificity (34%) in detecting CH which suggests that the participants with non-CH in this study (migraine and tension type headache) chose “excruciating pain” to describe their attacks.²⁸ However, the question addressed to patients “Is the pain severe and/or unbearable?” was interpreted by the authors as “excruciating pain”.²⁸

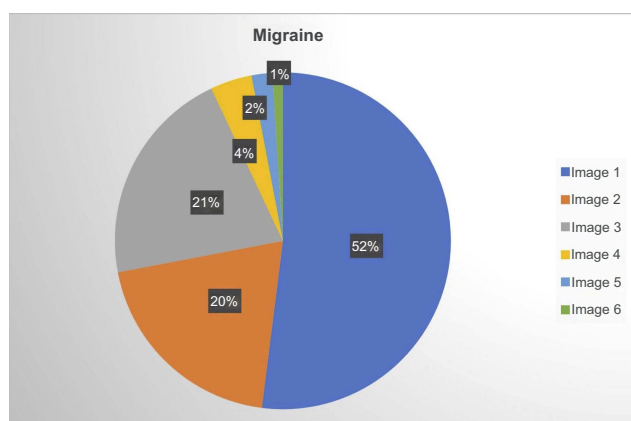


Figure 5 Image selection by participants with migraine.

Table 3 Image selection classified by diagnosis

| Image | Migraine (number of patients) | Cluster headache (number of patients) |
|---------|----------------------------------|--|
| Image 1 | 52 | 11 |
| Image 2 | 20 | 1 |
| Image 3 | 21 | 3 |
| Image 4 | 4 | 1 |
| Image 5 | 2 | 0 |
| Image 6 | 1 | 0 |

Image 5 was rated in the same way as image 1 by healthy participants although none of the participants with CH have chosen this image to describe their attacks. Image 5 not rated by 20% of the healthy participants. Although the reason was not captured, we could speculate that the level of pain depicted by image 5 is not clear to both healthy participants and participants with CH. Although migraine is described as moderate/severe pain in the literature,² 4% of participants with migraine chose image 4 rated as moderate by healthy participants. None of the six images in this study were able to differentiate between CH and migraine.

Strengths and limitations

This is the first study to explore the use of visual aids to assess and facilitate the diagnosis of primary headaches. The main limitation is that the ratio between participants with CH versus those with migraine (16 vs 100). However, this ratio reflects the prevalence of migraine (12%)²⁹ versus CH (0.1%).⁵ Although the images in this study did not differentiate between CH and migraine, the study did indicate the potential of using visual aids to depict headache severity.

Future directions

The aim of future research is to establish whether the findings of this study will be replicated in a larger study with a bigger population which is currently being undertaken.³⁰ The study is testing a screening tool for CH which includes images depicting pain, verbal descriptors of pain and key questions able to differentiate between CH and migraine.³⁰ A comparison of the characteristics of these two conditions will be performed, aiming to establish the clinical features that best differentiate between the two. Future studies could explore whether images depicting headache pain could be a useful diagnostic aid in patients with language barriers.

Conclusion

Healthy participants rated the six drawings in a new screening tool as showing a range of pain severities from mild to excruciating. Although both CH and migraine participants chose similar images to describe their headache attacks, the study indicated the potential of using images to depict headache severity.

Acknowledgment

We would like to thank Claudio Geraci for his work on the ARTe Cluster Project which inspired the research team to explore the potential of using images in screening for primary headaches.

Disclosure

FA served as an advisory board member and received honoraria from Allergan, Novartis, TEVA, Electrocore and Eneura, which he donated to charitable organisations (Migraine Trust, BASH and ADMA). The other authors report no conflicts of interest in this work.

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