The Migraine Tree: a shared tool for migraine information

A Árvore da Migrânea: uma ferramenta compartilhada para informação sobre migrânea

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ABSTRACT

Migraine awareness is a critical step in minimizing the disease burden. The Migraine Tree is a web structure designed by a Canadian team to inform people living with migraine and give them the knowledge they need to understand their disease and make daily decisions. This article summarizes the reasons for the creation of the Migraine Tree, its design and underlying principles and proposes future collaborations for translation in other languages.

Keywords: Migraine; Awareness; Education

RESUMO

A conscientização sobre a migrânea é uma etapa crítica para minimizar a carga da doença. A Árvore da migrânea é uma estrutura online projetada por uma equipe canadense para informar as pessoas que vivem com migrânea e fornecer o conhecimento necessário para entender sua doença e tomar decisões diárias. Este artigo resume os motivos da criação da árvore da migrânea, seu design e princípios subjacentes e propõe futuras colaborações para tradução em outros idiomas.

Descritores: Migrânea; Conscientização; Educação

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INTRODUCTION

The Migraine Tree is a web structure designed by a Canadian team to inform people living with migraine and give them the knowledge they need to understand their disease and make daily decisions. This article summarizes the reasons for the creation of the Migraine Tree, its design and underlying principles and proposes future collaborations for translation in other languages.

A need for therapeutic education tools

Therapeutic education has been recommended to manage chronic diseases.[1] A World Health Organization report in 1998 summarized its principles and benefits. People living with migraine make numerous decisions every day related to their condition and need the knowledge to make choices that will allow them to function and avoid negative consequences. A systematic review of therapeutic education for migraine found positive outcomes on quality of life, headache related disability, depression and headache frequency.[2]

The amount of information on migraine that has to be explained to patients is overwhelming. It cannot be synthetized in a busy clinic visit. Physicians may not have the time or communication skills to effectively counsel patients[3]. Education sessions have been found to be effective to improve outcomes and limit visit to the emergency department, but organizing and funding such sessions is not always possible[4]. The amount of misleading information available online is significant. People looking for reliable information can be bewildered by the numerous promises of cures and quick fixes. On the other side, scientific websites and blogs sometimes have too much unclassified information, making it difficult to find the topic needed. Every person with migraine has different needs. Attacks, symptoms, triggers and response to therapy vary. Having access to relevant, easy to understand information is crucial

for migraine management. Some resources are also written in a language for health care providers and do not necessarily address people's needs and concerns.

The Migraine Tree structure and design

The Migraine Tree is an original idea of Dr Elizabeth Leroux, a headache neurologist from Canada. After years of involvement in headache care and counselling, and previous web experiences with Migraine Quebec, she realized that a structure could help patients and health care providers to find what they need, contribute to a better understanding of the global approach and also have an educational value for health care providers not familiar with migraine management.

It was very important to choose a positive symbol for the structure. The Tree was chosen as a symbol of growth. Every culture, every country is familiar with trees. Trees assemble in forests, communities. They are resilient, they can lose their leaves and then grow new ones. They can bear flowers and fruits. Every person with migraine is part of a forest and can grow as new skills are learned.

The Migraine Tree uses a structure linking the network of the roots to the trunk and then to another network of branches. The structure was presented to patients during a focus group for feedback and the structure was found to be easy to use and understand. One interesting points the patients provided was that the the word «alternative therapies» was not used. This was a mindful decision, as opposing alternative and traditional medicine was not thought to be beneficial to patients. For example, some supplements have been shown to be effective for migraine prevention and acupuncture is also supported by evidence.

For some options at the Leaf level, two pages exist on a single topic: the WHY focuses on the rationale and proof of effectiveness. The HOW presents practical tips to use the treatment.

The Migraine Tree visual design was accomplished through a graphic design contest led by 3aLogic, a company based in Quebec. The final design was chosen

for its simplicity and colored in green and blue, in order to offer a soothing image. Images accompanying the texts were acquired in majority from the 123RF database and paid for by Migraine Canada. The team valued positivity, diversity and even humor to give an encouraging vibe to the readers. In the team's experience, people with migraine do not like to see images of pain and suffering repeatedly, as is unfortunately the case in the media.

The Migraine Tree is accessible online for free and with no advertising. A common problem in websites
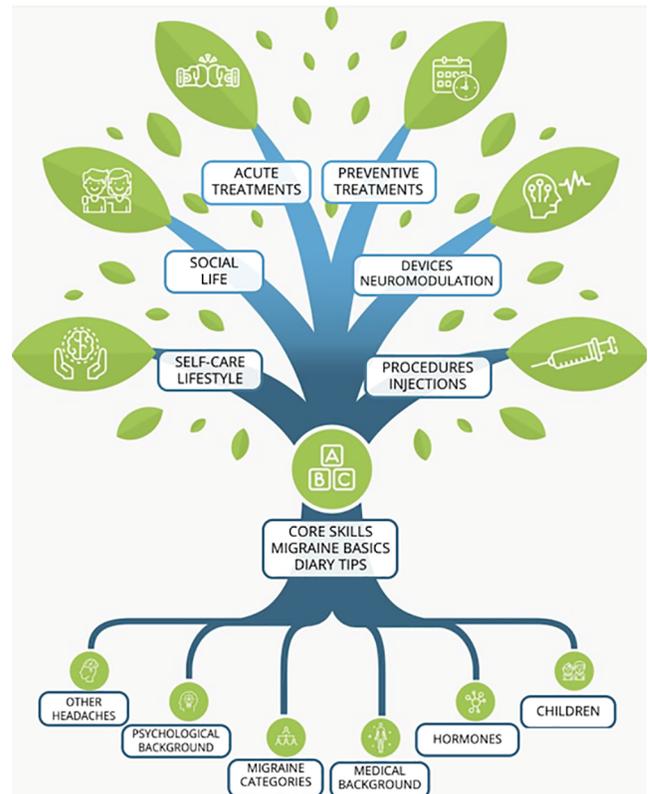

Figure 1. The Migraine Tree.

Table 1. The different levels of the Migraine Tree.

Level	Definition	Examples
Roots	The medical background and diversity of people with migraine.	Medical and psychological comorbidities
		Hormonal factors
		Pediatric syndromes
		Other headaches
Trunk	information that is relevant for most people with migraine at the beginning of their journey to improvement	Causes of migraine
Use of a diary		
Research and placebo response		
Branches	Treatment approaches are presented on an equal level.	Behavioral approaches, acute and preventive medications, neuromodulation
Leaves	Details on approaches, skills and treatments.	Individual medications, devices, skills

is the excess of distracting ads that may bother people with migraine who are photosensitive. It can be used in the clinic for teaching, the health care provider familiar with the pages being able to point out which topics are of interest from a particular patients.

The writing of the content

Topics were chosen and structured by Dr Leroux. Due to the large numbers of pages needed (close to 140), a team of Canadian writers was assembled. All writers were volunteers and agreed to decline authorship on the texts they provided. The guidelines of the Sick Kids Hospital from Toronto were used to determine format (PDF). The format chosen for most pages is a Question and Answer, that makes browsing for specific information easier. Questions were inspired from the clinical work of the health care providers who contributed. A checklist format has also been used, especially for the HOW pages. The pages have been limited to 600 to 900 words to avoid reading fatigue. The tone, format and style of pilot pages were reviewed by volunteer patient editors to provide guidance to the writers. Writers were instructed to write in an accessible and friendly way. They were encouraged to describe the typical challenges met by patients and choose words to empower them as much as possible. Some articles are more complex and may not be accessible to all readers but could benefit readers with higher literacy or scientific background.

In order to optimize search engine optimization (SEO), internal and external links were included in the pages. Key words and tags were selected. Scientific references were imported from Pubmed, prioritizing recent review articles.

A branch of the tree (Social Life) is still to be written by patients. This branch focuses on social impact of migraine and how to deal with relationships, school, and the workplace. Input from patients will be solicited through Migraine Canada in 2020. Engaging the patient community is extremely important.

Building a Migraine Tree community, sharing with other countries

The Migraine Tree was created in a spirit of sharing. The need for patient information of migraine is universal. Migraine is a common disease in all countries. Numerous resources are available in the English language, with the United Kingdom and the United States leading the way with well-organized and financially sustainable associations. For other languages though, resources are scarce. Headache associations don't always have the resources necessary to build elaborate educational tools. Reinventing the website wheel for each country, each association, would be time consuming for busy health care providers and volunteers alike. One of the goals of the team was to save time to other patient associations. In order to facilitate sharing, all the pages of the Migraine Tree are archived in a DropBox. Folders and pages all have an ID number. This archive is easy to share for translation.

Another important aspect of the Migraine Tree is its sustainability. As it is based on a hierarchical ensemble of numerated articles, it can be maintained relatively easily as knowledge progresses. Each article could be improved by requesting feedback from patients. As long as there is no duplication, new leaves can be added or even replace a similar leaf with a better version that can then be translated in other languages, a bit like the articles of the Wikipedia encyclopedia. Pages containing country-specific data would need to be adapted (lists of medications, coverage comments).

In order to improve the Migraine Tree, feedback from users should be gathered in the future, both from health care providers and patients.

CONCLUSION

The Migraine Tree is a new online structure offering people with migraine a wealth of reliable information in a format that is easy to browse. Future collaborations could be developed with other countries to make this information accessible to more people.

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