A mapping study to compare the educational offerings for patients of multiple sclerosis and HIV in Europe and Canada

Peter Rickmann1, MD and Dawn Langdon2, PhD on behalf of the MS in the 21st Century Initiative, and Elisabetta Verduin di Cantogno, MD, PhD
1Medical Park, Loipl, Germany; 2Royal Holloway, University of London, UK; 3Ares Trading S.A. – An affiliate of Merck KGaA

Introduction

• The MS in the 21st Century initiative, formed in 2011, is composed of a Steering Group of international multiple sclerosis (MS) specialists and a patient group with MS (MSiW). The initiative’s current focus is to improve education of, and communication between, HCPs and PwMS.
• In 2015, MS in the 21st Century conducted a mapping exercise to explore the existing educational offerings for PwMS in Europe and Canada (Phase 1). This Phase 1 study showed that resources for MS were provided by a broad range of stakeholder types with some topics represented more than others.
• The aim of Phase 1 was to determine whether there was a difference in the existing educational offerings for MS. In order to provide a measure of reality, it was necessary to compare the resources available for MS with the educational resources of another comparable condition (Figure 1).
• The MS Group selected human immunodeficiency virus (HIV) as the comparator disease because both HIV and MS are chronic and incurable immunocompromising diseases with similar age demographics. Both diseases require patients to remain on lifelong treatment regimens with side-effects that have the potential to greatly impact on quality of life.

Objectives

• To compare the number, format and topic of patient educational resources, and the stakeholder type from which they appear, in the field of MS to those in HIV.
• To identify areas where the educational offerings for MS may differ, or are lacking when compared with HIV.

Methods

• Desktop research using country-specific URLs of the Google search engine was designed to obtain results that were as representative as possible of what resources a patient in each country would have access to online. Stakeholders were identified across 20 European countries, and results were then filtered and assessed based on a list of stakeholder types, pre-determined by the Steering Group, in combination with the disease name (MS vs HIV).
• Stakeholder websites were then explored in full and all relevant pages were recorded as resources in a database and categorised by format, topic, stakeholder type and country (Table 1).
• Resource format and resources from the four least represented overarching topics were represented by percentage (Figure 2).
• Overarching topics (for each MS and HIV resource topic) are shown in Figure 3. The overarchign topic was listed as ‘other’ when related to a number of different areas.

Results

• A total of 373 stakeholders were mapped for HIV, resulting in the identification of 249 resources; compared to 3,542 resources from 137 stakeholders identified for MS. The median number of resources per stakeholder was 6 for HIV compared with 5 for MS.
• For PwMS (58.1%, n=368) and MS (60.2%; n=3217) the majority of resources came from patient associations/advocacy groups (Figure 4).
• Government or public health providers were a greater source of resources for HIV (10.7%; n=368) than MS (2.8%; n=120).
• More resources for HIV than MS came in the format of downloadable information sheets (31.1%; n=436 HIV; 14.3%; n=228 MS) and booklets (22.6%; n=313 HIV; 15.3%; n=228 MS) (Figure 5).
• The most frequent overarching resource topic for MS was general information (25.1%; n=1376) followed by treatment (21.0%; n=1213), whereas the most frequent topic for HIV was treatment (45.4%; n=436 HIV) (Figure 6).
• The most frequent overarching topics across the two fields were information for families and caregivers (1.8%; n=14 HIV; 3.4%; n=60 MS), communication with healthcare professionals (2.5%; n=131 HIV; 3.7%; n=329 MS), physical symptoms (5.1%; n=82 MS; 3.4%; n=51 HIV) and invisible symptoms (7.0%; n=137 MS; 5.0%; n=82 HIV) (Figure 3 and 4).

Discussion

• The references that can be drawn from the data are limited due to the purely narrative nature of the study. No assumptions were made about the quality of, or engagement with, the resources and only direct comparisons between the relative proportions of resource availability have been conducted.
• A lack of public awareness around MS may be one factor in explaining why a larger proportion of its resources come from social media stakeholders than for HIV. PwMS may feel more comfortable talking about their disease openly in public without fear of any existing stigma and might also feel that it is their responsibility to raise the level of public awareness, making them more vocal in social media sources than for HIV.
• In addition, MS symptoms can affect PwMS’s ability to spend large amounts of time outside the home, potentially resulting in a greater reliance on the internet for social interactions.
• A high level of public awareness about HIV since the 1980s might have translated into a larger amount of high quality printable resources from centralised organisations (government or public health providers) and less emphasis on grassroots awareness relative to MS. This could also explain the larger number of resources per stakeholder seen in MS compared to the more diverse educational landscape for HIV.
• The MS educational landscape offers fewer resources on social/legal information, which covers topics such as employment rights, compared to HIV. This is a potential gap in the educational landscape of MS, considering that MS symptoms can have a ramped on PwMS in the workplace.
• Considering the traditional marginalisation of such issues, the higher number of resources covering the invisible compared to physical symptoms of MS (including mental health issues) is not surprising.
• The higher number of alternative treatment resources in MS potentially represents a greater amount of misinformation about the disease. This may be due to the more diverse educational landscape compared to HIV.

Conclusions

• These Phase 2 data showed that the educational resources for both MS and HIV come from a number of different sources and cover a wide variety of topics. While there were many similarities between the educational offerings of the two diseases, there were also many differences.
• It is clear that stakeholders are learning, more frequently, to the internet for information about their health. Therefore, it is essential to ensure that the resources they are accessing online are relevant and accurate and that their HCPs are able to guide them to these resources.
• This study may be expanded on by surveying PwMS about how they access and interact with online resources.

References


Acknowledgements and disclosures

The MS in the 21st Century initiative is financially supported today by Merck KGaA, Darmstadt, Germany. Silential support and editorial input was provided by Cello Health Communications. Medical writing assistance was provided by Cello Health Communications (Owen Webb and Fiona Hatch) and was funded by Merck KGaA, Darmstadt, Germany.

MS in the 21st Century Steering Group members