Education material for Multiple Sclerosis: Brazilian eBook

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BACKGROUND

Due to the unpredictable course of Multiple Sclerosis (MS), information about the disease is essential for people to develop coping and care skills.

OBJECTIVE

To analyze and improve the readability and adequacy of patient and family education materials from the Brazilian Multiple Sclerosis Association (ABEM).

METHODS

Thirteen original educational materials in flyers format written over the institution's 37 years were reviewed by a neurologist. Three MS experts then compared the original and revised materials using the Suitability Assessment of Materials (SAM) instrument, a grading scale used to evaluate suitability of health information materials for patients. Afterwards, six MS patients and two family members were interviewed to discuss the revised materials, the feedback was analyzed qualitatively. Pearson correlation was calculated to determine inter-observer correlation between SAM scores assigned by the three evaluators. Paired t test was used for analysis of SAM scores between original and revised patient education materials.

RESULTS

It was observed that no specialist evaluated the original or revised flyers as unsuitable; however, the revised flyers represent a significant improvement in total SAM score compared to the original flyers. Specifically, SAM score improved from 60% (adequate) for the original versions to 98% (superior) for the revised flyers ($p < 0.001$). Finally, the revised flyers were converted into an eBook containing information about the disease and guidance on how to care for a family member, swallowing, depression, emotion, behavior, fatigue, speech, hypertension, memory, falls, vision, osteoporosis and insensitivity on the feet.

CONCLUSIONS

The stages of elaboration and review of ABEM's educational materials resulted in a relevant digital tool aimed at the reality of people with MS for health promotion, prevention and self-care. In addition, the eBook is appropriate, practical and useful to family members and caregivers, favoring the expansion of support for these people.

BIBLIOGRAPHIC REFERENCES

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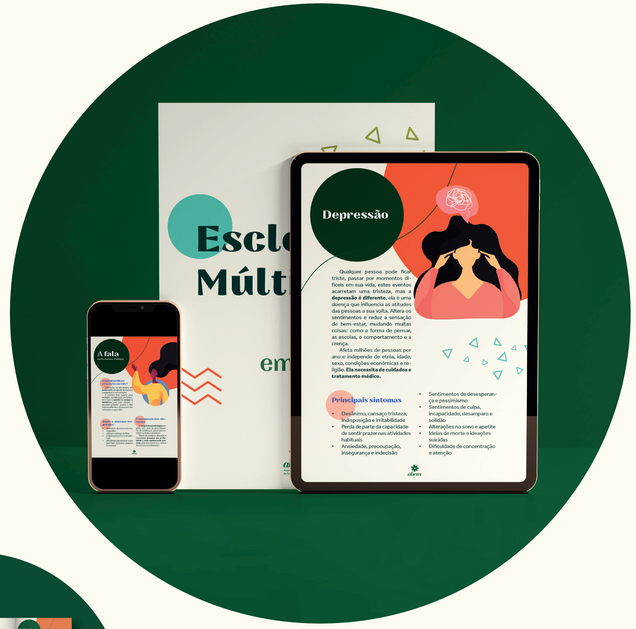

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