INFORMATION IN MULTIPLE SCLEROSIS: DO PEOPLE WITH MS WANT TO KNOW ABOUT THEIR DISEASE?

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ABSTRACT

Introduction: Several studies have outlined communication and information deficits in the care of people with Multiple Sclerosis (PwMS). The aim of this study was to evaluate how and where patients follow information about Multiple Sclerosis (MS).

Methods: A cross-sectional study based on a self-administered survey about the main sources of information about MS, from August to December 2019.

Results: 103 individuals answered a self-report questionnaire. Concerning information about MS, the medical visits (76.7%) were the main source to obtain understanding or new information, followed by the internet (48.25%), social media (22.3%), and other patients (24.5%). 34.7% of patients understood very well the information, but 46.7% reported some difficulty in understanding, while 18.4% did not understand it. When asked about their participation in choosing or in the change of their treatment, patients reported that 39% fully participated, 29% partially participated, and 32% did not participation in choosing or changing treatment.

Discussion: we identified the PwMS use medical consulting as the main source of information. Although the internet is an important source of information, it does not provide the necessary personal contact. PwMS had difficulty understanding the information from different sources, as well as participating in the choice of medication. The development of autonomy in PwMS is fundamental. In this way, PwMS needs to have sufficient and appropriate information to be able to express their preferences, because they want to know about disease, the impact in their lives and how improve their life quality.

Conclusion: it’s necessary to improve our ability to communicate with patients. Patient autonomy and shared decision making can play an essential role to avoid patients to choose options of no proven benefit. One possible is creation of communication channels to adjust to the reality and expectations of patients and involve patients, relatives and multidisciplinary team in medical decisions.