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BACKGROUND

MS affects young people at productive age with repercussion on the rest of their lives

Assistance in MS can be very extended and bureaucratic and the main focus is often about relapses and treatment.

There are a lot of important aspects that have impact on quality of life and many times are left on the side.

On this issues, it is about poor disease-related knowledge among people with MS

Several studies have outlined communication and information deficits in the care of people with MS as well as differences between patients and physicians concerning decision process.

OBJECTIVES

The aim of this study was to evaluate how and where patients follow information about Multiple Sclerosis.

METHODS

A cross-sectional study based on a self-administered survey about the main sources of information about MS with People with Multiple Sclerosis (PwMS), from August to December 2019 in Santa Casa de São Paulo.

RESULTS

103 individuals answered a self-report questionnaire, average age of 40.6 years, female predominance (80.6%) and 60% self-reported as Caucasian.

Most of them want do know about their disease, direct or indirectly (fig.1).

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%).

Do you want to know about news? (%)

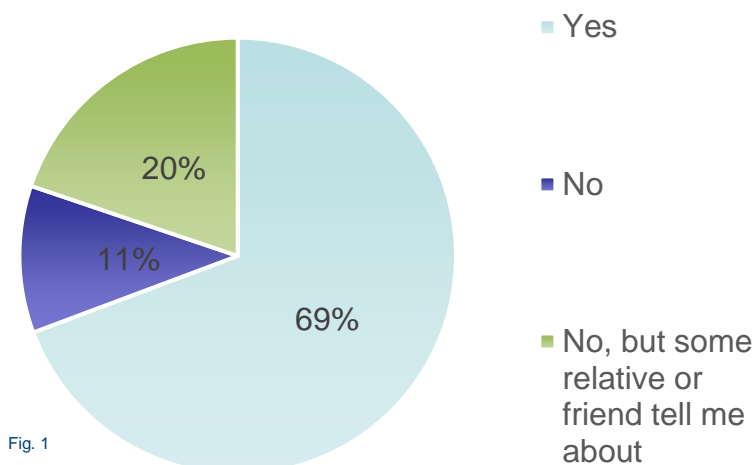


Fig. 1

34.7% of patients understood very well the information, but 46.7% reported some difficulty in understanding, while 18.4% did not understand it (fig. 2).

Understand information (%)

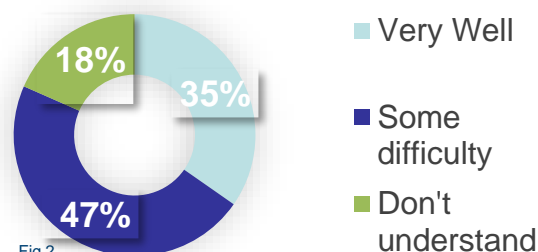


Fig.2

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 research MS; this result was similar with other study where 85% pwMS felt information should be provided in the neurologists' office. Although research on the internet is an important source of information, it does not provide the necessary personal contact for PwMS. PwMS had difficulty understanding the information from different sources, as well as participating in the choice of medication. In this way, PwMS needs to have sufficient and appropriate information to be able to express their preferences. The development of autonomy in PwMS is fundamental, since MS affects young and active people, so it is expected that them 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 decisions about their disease.

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