

Information Provision and Quality. A Pilot Study on Shared Decision-Making in Multiple Sclerosis

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Abstract. The patient as an active participant in decision-making has become an important resource in health care. Shared decision-making (SDM) relies on the patient's easy access to reliable and evidence-based health care information as well as the availability of patient-generated data, such as values and preferences for the health care professional (HCP). The aim of the present pilot study was to evaluate what type of information people with multiple sclerosis (pwMS) use in the SDM process, and what are the sources of that information. A semi-structured web-based survey of SDM was conducted through the MS-society in Finland. The results are presented against the Ottawa Decision Support Framework. A total of 27 pwMS participated. We found that all the participants wished to be involved in the decision-making process, but that they seldom found the information provided by HCP to be helpful. Instead, they searched the internet and visited various conversation platforms in social media, such as Facebook groups, for additional information.

Keywords. Patient participation, shared decision-making, multiple sclerosis

1. Introduction

Patient autonomy and centeredness are crucial components of high-quality health care services. Shared decision-making (SDM) is a strategy to implement patient centeredness in clinical decision-making. In SDM, patients and health care professionals (HCPs) make care decisions together, which promotes patient autonomy [1-3]. It has been shown that patients prefer SDM, and patients involved in it experience better health outcomes and satisfaction [4-5]. A successful SDM process relies on high quality health information as well as patient-generated data together with the experience of HCPs [6].

Multiple sclerosis (MS) is a chronic degenerative and inflammatory disease of the central nervous system. It is the most common neurological disease among young adults, leading to severe disability. Two thirds of the patients are female [7]. In this study, people with MS (pwMS) were selected as a target group, since MS is a typical preference-sensitive condition, in which there are multiple treatments with similar efficacy but different safety profiles, follow-up and administrations [8]. The aim of the present study was to evaluate what type of information pwMS use in SDM and what are the sources of that information.

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2. Methods

A semi-structured web-based survey containing 17 statements using a five-step Likert scale was open to pwMS who had been advised to start disease modifying medication or switch medications within 30 days. The statements were grouped according to the Ottawa Decision Support Framework in order to measure information sources (decision quality) and types of decision support [9]. The Survey was distributed through the Finnish MS Society on the society website. The data was analyzed using descriptive statistics.

3. Results

A total of 27 patients participated. Of the respondents 25 were female and the age ranged from 23 to 55 years. All respondents either strongly agreed (15 %) or somewhat agreed (85 %) with the statement “I want to take part in deciding on my medication”. In addition, 92% felt that the care decision is made together with the doctor. Furthermore, the majority (67 %) of the respondents felt that a next of kin or a friend should be involved in the SDM process, but only 30% considered that their opinion influences the decision. The results for decision quality are presented in Figure 1 and for decision support in Figure 2.

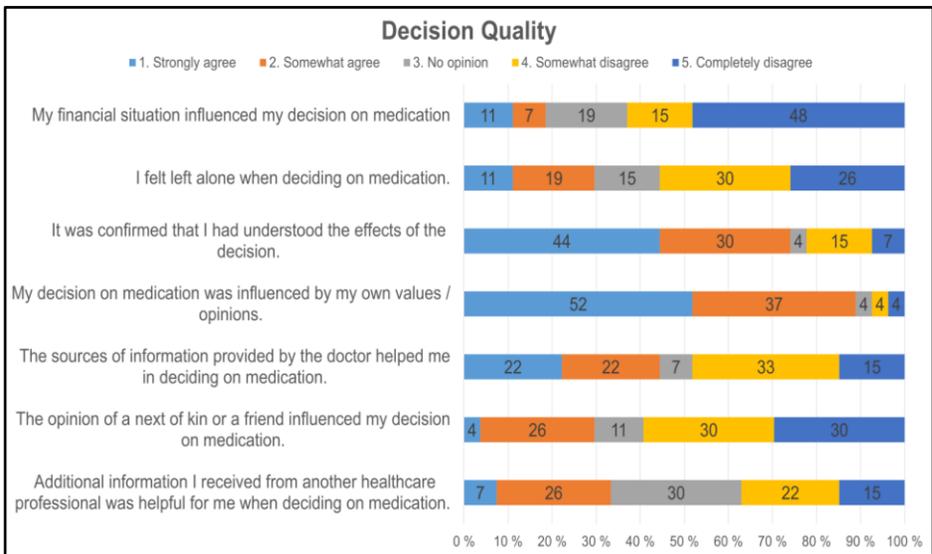


Figure 1. Ottawa Decision Support Framework: Decision quality

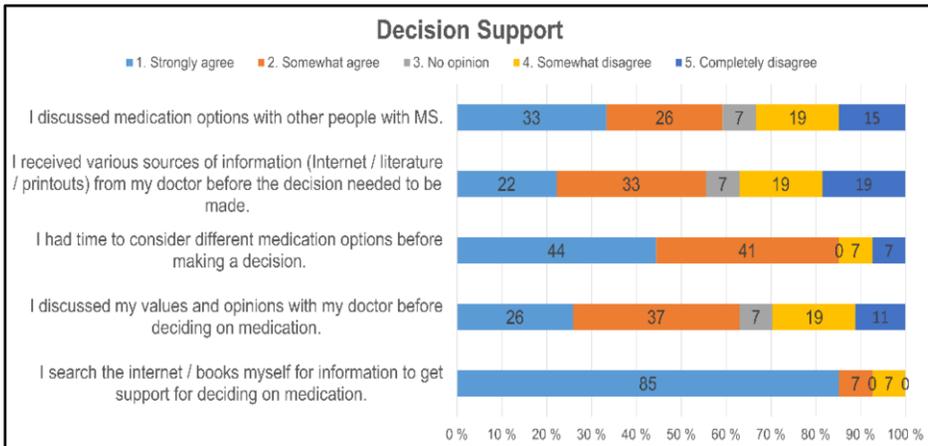


Figure 2. Ottawa Decision Support Framework: Decision support

4. Discussion

Patient empowerment is a process allowing patients to gain control of their health and health care. In order to be able to take part in treatment decisions, patients need to be sufficiently informed and educated. Indicators for empowerment include health literacy, knowledge, participation in shared decision-making (SDM) and self-management [2]. The present pilot study shows that even though patients are and want to be involved in SDM, the information provided by health care professionals (HCPs) is rarely useful for the patient. Even today, the information provided by HCPs is most often booklets and other paper material, which may seem outdated and unreliable to some patients. According to our findings, many pwMS seek information on the internet and especially on various conversation platforms before deciding on a suitable medication. Similar findings were reported recently in a scoping review by Rahn et al., which included 14 studies on information provision and patient education in SDM in MS [3]. In addition, electronic educational programs have been found to be superior in increasing the knowledge of patients with MS compared to booklets [10].

In line with our findings, previous reports have shown that information on the internet is considered useful by pwMS [11,12]. Furthermore, information on social network sites has been found to increase support, information, and awareness to pwMS, and appointed influencers on internet sites are considered reliable by pwMS [3,13]. On the other hand, pwMS may find it difficult to recognize reliable information on the internet [3,11-13]. There are numerous and various MS apps [14], but to our knowledge, their usefulness or reliability in delivering high-quality information for pwMS has not been studied.

Health literacy, i.e., the subject’s ability to understand written health-related information, is an essential part of the SDM process. Studies on health literacy of pwMS are sparse, but according to a review by Rahn et al., it appears that health literacy is most likely not impaired due to MS [3].

We conclude that pwMS wish to participate in the SDM process, but they frequently find the information provided by HCPs to be of limited use. Instead, they rely on information found on the internet. In an era of rapid digitalization of health care, HCPs and information technology specialists should work together to find ways of providing patients with evidence-based, reliable, up to date and high-quality electronic information.

5. Acknowledgements

This research was funded by the Strategic Research Council (SRC) established within the Academy of Finland. Funding no. 335288

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