This theme issue of IJMSC deals with patient involvement in managing multiple sclerosis (MS), specifically regarding so-called disease-modifying drugs in MS. Shared decision making (SDM) is increasingly recognized as the preferred health care approach. Patients’ autonomy is the bioethical principle behind SDM and has recently been emphasized as one of the main principles of the Revised Declaration of Geneva. However, while SDM is a bioethical principle, it is less clear if it leads to better health outcomes. In addition, health economic savings have been claimed, but still with little evidence. Even without proof of these benefits, SDM is a bioethical must and a quality-of-care indicator by itself. The articles in this issue add to understanding of the topic in the MS field.

Col and colleagues from the United States report on data from a new Web-based tool that helps patients to reflect on and structure their preferences. Among 135 patients with MS, no two of them had identical preference profiles—demonstrating the complexity of treatment decision making. Interactive e-health tools might be one strategy to alleviate this process. Thach and colleagues analyzed a NARCOMS (North American Research Committee on Multiple Sclerosis) Registry study sample of 489 people with long-standing MS to look for treatment satisfaction and adherence. Although 93% of the participants with MS reported being DMT adherent, younger patients, patients taking injectable treatments, and patients with prior treatment experience were at higher risk for nonadherence. However, all survey-based research on adherence has a substantial bias towards high performers, which is reflected in high adherence rates. Additional approaches are needed to really understand nonadherence in MS. Schlegel and Leray observed 29 patients with MS during visits to their neurologist in France and then performed interviews with 15 of them. The authors observed that it was mostly the neurologists who decided whether the patient was involved in decision making. The authors argue that when neurologists neglect patients’ will, noncompliance might be the only way for these patients to communicate their preferences. In this issue’s CME/CNE article, Ben-Zacharia and colleagues from the United States provide a narrative review on SDM and adherence touching on the issue of outcome measures. Indeed, all questionnaires are heavily distorted by social desirability on all sides (here, patient and physician), and we still lack robust outcomes so that the quality of communication processes can be classified. Ratings of audio- or video-recordings of encounters remain the gold standard of assessment. Ben-Zacharia et al. conclude that interventions to increase adherence based on an SDM model need to be developed together with additional work to better understand nonadherence. Finally, Lynd and colleagues from Canada report on results from three focus groups with 23 total patients. Ten of these patients were treatment naive, and their attitudes about new medication were studied. Convenience of the route of administration was not a major topic, but the unknown risk profile of substances newly on the market was.

Patients in the survey from Col et al. indicated that beyond influencing the disease process, having a knowledgeable and compassionate medical team was a high priority in the specific preference item ranking. This patient poll points to a prerequisite of patient involvement often not touched on in SDM research. It has...
been argued by medical philosophers that without trust patient autonomy is not possible. Thus, the emotional and social surroundings are highly relevant for any SDM attempt. Instead of being a marketing model for a purely consumerist or a nicely wrapped paternalistic approach in a “shopping center for health care,” SDM is an elaborated interaction model built on a trustful relationship.

What has not been addressed in most studies on SDM in MS, but is reflected in the currently revised Cochrane review on information provision in MS, is the paucity of studies on patient information delivery in MS. Nonetheless, defining the minimum amount of necessary information and the adequate mode of presentation in terms of understandability is far from straightforward. Because evidence-based patient information is crucial for SDM, much more work is needed to discover the most suitable strategies for conveying the complex evidence and uncertainties in the MS field. Outcomes are missing as well in the area of patient education. An international consensus on the ten most important facts about MS therapies to know might be a starting point.

Decision coaching by educated MS nurses is a possible approach that would allow patients to ask questions that they would not feel comfortable raising during physician encounters. Such coaching could be easy to implement and highly tailored. Pilot work indicates that this approach is effective for making decisions about immunotherapy in MS.

While immunotherapy is probably the most challenging decision-making area in MS, from a scientific and human standpoint, many other decisions are necessary for people with MS. Choice about motherhood in this regard is a highly complex matter in early MS. Later transition to secondary progressive MS can be similar to receiving a new diagnosis, and it seems that often such information about the disease now having become chronic is withheld for numerous reasons. Although little work has been done regarding the views of people with MS in the secondary progressive phase, Giovannetti and colleagues, supervised by A. Solari, recently initiated the ManTra (managing the transition to secondary progressive MS) project with support from the Italian MS Society to look at the needs of patients with MS in this disease phase. Finally, palliative care is substantially underinvestigated in MS. Research about palliative care is also hampered by it being mentally connected to the idea of terminal illness, and thus considered a taboo topic. The European Academy of Neurology is currently working on a clinical guideline about palliative care in MS, which will presumably show substantial knowledge gaps. However, SDM has been studied in palliative care in oncology, which possibly best represents the area in medicine where care without patient centeredness is virtually impossible.

Beyond caregivers and relatives, other patients have the potential to substantially support decision making. Whereas in the past self-help groups were a strong pillar in peer support, many patients nowadays have moved to the internet where a wealth of unverified information is available and where personal responsibility and deep bonding with others is often low. Among chronically ill people, individuals with MS are among the highest-frequency internet users. With platforms such as healthtalkonline.org based on the DIPEx methodology (www.dipexinternational.org), strategies have been developed to sample patient experiences based on short videos clips in a highly transparent and balanced way. (To date, MS is represented in video form on healthtalkonline.org only from a caregiver perspective, with experiences of people with MS not yet being shown.) And, to our knowledge, the potential impact of patient experiences on decision making and adherence has never been studied in MS. Putting the patient voice onto internet platforms in an educated, systematic way has the potential to affect the overall public perception of MS and might reveal unmet needs.

The understanding and fulfillment of the educational needs of people with MS and their families are prerequisites for true SDM. A major session on this topic will be held during the 2019 CMSC Annual Meeting in Seattle, Washington, on May 31. You are invited to join!

References