


Patient Power Revolution in Multiple Sclerosis: Navigating the New Frontier

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Abstract: A debate on shared decision making in multiple sclerosis (MS) was led by a patient advocate and leading neurologists from the MS in the 21st Century Steering Group. Key themes and salient points which emerged from the debate and audience discussions are reported in this article. Arguments against shared decision making included the fact that physicians study and practice for years to reach their level of expertise, and that the level of understanding required to make these decisions may not be possible to communicate to patients within time-limited consultations. Furthermore, unreliable online information, information overload or information with marketing bias may also

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cloud patients' judgements. Arguments for patient engagement focussed on how ownership of decisions can lead to improved adherence and outcomes, and a strengthening of the physician–patient relationship. Shared decision making requires educating patients to make informed decisions and to understand the risks and consequences of their choices. However, shared decision making may not be the correct option for every patient, and the level of involvement must be driven by the patient. To support patients' engagement and promote responsible management of their condition, physicians need to (1) foster and maintain a positive, ongoing relationship with their patients, and (2) provide patients with timely, accurate, and understandable information. There was broad agreement that the patient voice should be heard more in discussions around the future of MS care. MS in the 21st Century offers a model for patient involvement in partnership with MS healthcare specialists, and the steering group is currently considering these issues and developing tools and solutions to enhance patient–physician communication and relationships.

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INTRODUCTION

Like many aspects of medicine, care in multiple sclerosis (MS) has historically been paternalistic in nature, with healthcare professionals (HCPs) typically making treatment decisions independently of patient preference. However, there is now a sweeping shift towards increased patient engagement, defined broadly as the ‘active involvement of patients in their own care, in order to enhance safety, quality and people-centredness of health care service delivery’ [1]. Patient engagement is widely considered to be the gold standard for ethical care; this includes giving patients greater ownership of their healthcare through shared decision making and recognition of the patient perspective at all levels, from discussions about individual care through to organisational or national policy [2, 3].

With increased recognition of the importance of the patient voice, there are now many initiatives to facilitate and support shared decision making in health (e.g. National Health Service England’s commitment to shared decision making, or the Centre for Advancing Health’s report *Here to Stay: What Health Care Leaders Say About Patient Engagement*) [4, 5]. In MS, research has been undertaken to investigate how well patients with MS (pwMS) understand their treatment and how communication between pwMS and HCPs can be improved [6–9].

MS in the 21st Century is an international group of patient advocates and HCPs, collaborating to raise awareness of, and identify solutions to, issues in MS care. Together, the group has developed MS care consensus statements and identified unmet care needs [9, 10]. As part of their programme of challenging the MS status quo and disseminating their perspective of patient engagement and advocacy, MS in the 21st Century hosted a symposium on 2 December 2017 at the European Charcot Foundation, an influential neurology conference attended by internationally recognised neurologists. Led by a patient advocate and leading neurologists from the MS in the 21st Century Steering Group, the symposium took

the form of a debate on the involvement of pwMS in shared decision making.

Although MS in the 21st Century is committed to advancing shared decision making, it was recognised that the need for caution regarding patient engagement must also be considered on ethical and clinical grounds. Treatment requires informed consent; patients may choose not to hear about treatment risks, but information about other aspects of the treatment options should still be discussed if possible. However, not all patients would want the responsibility or complexity of involvement in their treatment or other health decisions [11]. For example, patients with higher disability and more relapses might be more interested in shared decision making, perhaps perceiving that prior treatment decisions have not worked optimally for them [12]. Both sides of the argument were presented in the context of MS.

In line with MS in the 21st Century’s philosophy of collaboration and mutual respect between pwMS and HCPs, consultation and drafts of the content and format went through many iterations, informed by all members of the steering group. The debate was chaired by neuropsychologist Dawn Langdon, with neurologists Gavin Giovannoni and Peter Rieckmann presenting opposing views, for and against patient involvement in shared decision making, and patient advocate David Yeandle providing the patient voice. The aim was to elicit contributions from the audience and stimulate discussion among those attending. Here we report the key themes and salient points which emerged from their discussions.

AGAINST PATIENT ENGAGEMENT

When the movement for greater patient engagement in MS began, only two therapies (interferon beta and glatiramer acetate) were available [10, 13]. However, rapid advances in recent years mean that there are now 17 different therapies available, creating a complex treatment landscape. Physicians study and practice for years, even decades, to develop expertise in their chosen therapy areas; it is unreasonable to expect every patient to fully

understand the underlying aspects of their condition, the options that are available for its management, and the consequences of their choices in terms of efficacy, mechanisms of action, and potential adverse effects. Sadly, physicians cannot give each patient the time needed to fully explore and educate them on each option prior to embarking upon treatment. Furthermore, patients can be influenced by external sources of information, such as promotional marketing, that physicians may struggle to identify and balance against.

The concerns about overwhelming patients with the amount of information necessary for shared decision making were laid out in a recent paper showing that a paternalistic approach, whereby physicians make choices on behalf of their patients' well-being, has historically been typical for medicine [14]. In many cases, physicians have experienced situations where patients have been overwhelmed by options and information, leading to confusion or anxiety. Often, both parties have found it beneficial for the physician to take the lead in making clinical decisions [14]. However, it is important to note that a paternalistic approach to care is not incompatible with shared decision making; delegating the decision-making to their physician or neurologist is one of the options available to pwMS.

The audience mentioned that patients rarely foresee probable outcomes with the same clarity as an experienced physician. We all tend to be more optimistic about our own health and to prioritise short-term outcomes over longer-term ones. Physicians have a greater level of expertise and objectivity when predicting patient outcomes than pwMS may have for themselves, and it is understandable why many pwMS are reluctant to accept a lifetime of pharmaceutical therapy; these differences in expectations can make shared decision making challenging for both physicians and pwMS.

Ultimately, the responsibility for the patient lies with the physician. It may not always be easy for a physician to make a decision, but they know that, more often than not, they can trust their own judgement and that they accept the responsibility inherent to this decision. Patients do not have years of education and expertise

within a therapy area, and giving them the responsibility for treatment decisions and their outcomes may be doing them a disservice when the focus should be on supporting them to manage and live with their condition.

FOR PATIENT ENGAGEMENT

Greater involvement in disease management has been shown to improve patients' ownership of and commitment to therapy; patient engagement is often referred to as 'the blockbuster drug of the 21st century' [15]. In broad terms, greater patient engagement leads to improved outcomes (measurable in terms of adherence or mortality), reduced healthcare consumption (as measured by diagnostics, referrals, and direct healthcare costs), and improved service quality (measurable through communication, patient health literacy, healthcare staff retention, and HCP–patient relationship satisfaction) [10, 16–21].

If we expect pwMS to adhere to their treatment regimens and appointment schedules, we should also give them some say and agency on how their disease is managed. A key aspect of patient engagement is the recognition that patients are individuals, with different needs, lifestyles, and priorities. By involving patients, care teams can come to decisions which are most appropriate for the individual, taking all of their life circumstances into consideration, not just their disease.

Poor adherence and discontinuation of treatment prevent the effective management of MS, with several real-world studies indicating that within a few years of initiating treatment, about 30% of pwMS discontinued or were non-adherent to their therapy regimen [22–25]. Patients who do not feel they have a say in clinical decision making, and who lack in-depth understanding and realistic expectations of their care choices, are more likely to be non-adherent or discontinue therapies entirely [26]. Conversely, patients who are involved via shared decision making are more likely to feel a sense of responsibility for the management of their condition, which translates into greater

satisfaction, better adherence, and improved outcomes [10, 27, 28].

FINDING THE RIGHT BALANCE

The two positions discussed above are not mutually exclusive. Whilst there is no disputing the expertise that physicians bring to a consultation, when physicians guide treatment decisions, they must, in turn, be guided by the individual patient's expressed best interest. The patient is always the ultimate arbiter, as it is they who decide whether they adhere to the treatment and regularly introduce the drug into their body. However, it is often not optimal to give all of the responsibility to the patient. The audience raised the point that handing patients a leaflet and asking them to come back with their decision is a more dangerous approach than pure paternalism. Truly empowering patients means educating them to make informed decisions, including understanding the risks and consequences of their choices.

Historically, physicians have been the gatekeepers for access to both therapy and disease knowledge. In the age of information technology, the latter role has been severely compromised, sometimes leading to a loss of faith in doctors. While there is a wealth of information available online, unfortunately, not all of it is reliable, and some of it is misleading or even dangerous. Patients with MS can therefore struggle to navigate this sea of information without guidance, and simply leaving them to do so by themselves is unhelpful for patients and their relationship with their HCP [29]. Unsurprisingly, pwMS who better understand their disease and treatment tend to be more engaged and show greater treatment adherence [30].

Scripted education programmes can improve disease knowledge; however, they do less well at enhancing decision making and quality of life [31]. Whilst patient organisations often produce high-quality information which is useful background reading, they cannot know the individual patient's profile and customise information to their particular circumstances. Some pharmaceutical companies offer support

programmes to patients on particular medications, but these have not been objectively evaluated. Overall, it seems that individual consultations that are tailored to the individual by the HCP, and which allow exploration of preferences, fears, and priorities, are the most useful.

It was noted that pwMS should be supported to feel comfortable discussing difficult topics. The presence of a family member can be helpful for these discussions, and patients often view their treatment decisions and adherence as activities to be shared with their family support network [32]. The perception of an open dialogue and trust with their physician contributes to patient satisfaction [33]. In order to support patients' engagement and promote their management of their condition, physicians need to (1) foster and maintain a positive, ongoing relationship with their patients, and (2) provide patients with timely, accurate, and understandable information.

However, it is important to remember that information does not equal education, and the ability to make the complexities of medicine comprehensible for patients is an important skill. Physicians must consider not only what they communicate, but also how and when this is done in order to ensure they educate rather than mystify or mislead. Sadly, physicians often have little, if any, formal training in soft skills such as communication and conflict management [10, 34–37]. It was noted that, like most precious things, a trusting relationship between a patient and their physician is difficult to create and develop, but all too easy to damage.

Medicine relies on a clinical evidence base, but it is not a pure science. Much of it is an 'art', informed by an HCP's experience with their patients. Tailoring patients' involvement according to the physician's experience and clinical intuition would be essential in any shared decision-making system. One cannot ignore the fact that more choices make for more complex discussions. Physicians should therefore be able to personalise their approach as appropriate, even if that means restricting the range of choices presented to some patients. Even when decision making is not shared,

explaining the rationale behind the choices the physician has made can strengthen the relationship with their patient and improve engagement. Inviting comment and discussion may reveal information which may cause the physician to reconsider the optimum choice they have made.

The audience noted that, when shared decision making takes place, physicians must accept that patients will not always ultimately choose the option a physician might have recommended. It is important that a trusting relationship exists, in which both parties can share a dialogue and push back against decisions they disagree with. If a pwMS persists with a choice against their physician's advice, it is important that the physician respects their patient's wishes and continues to provide the best support they can within the constraints of the patient's decision. Within a positive and open relationship, patients have room to return and consult their physician if their chosen option is not meeting their needs. In the context of a chronic disease, the relationship is ongoing and, as the relationship develops, both parties have opportunities to learn from one another. As this experience grows, an open, honest, and mutually respectful relationship can hopefully develop, and patients are then more likely to trust their physician's advice.

Several participants noted that the greatest challenge for patient empowerment and a positive patient–physician relationship is the restriction on physicians' time. Given these constraints, it is important that appointments are used optimally for effective communication. During the debate, participants stressed that, while it is crucial that physicians listen to patients, research indicates that patients are often interrupted after only 23 seconds of speech [38], despite only taking an average of 92 seconds to relay their concerns if allowed to talk without interruption [39], and that this can lead to misunderstandings and assumptions. Physicians must use their clinical skills to support patients who may struggle to make their point, get bogged down in irrelevant information, or have difficulty expressing their message clearly.

Accordingly, it is worth considering how the appointment process could be adjusted to better benefit pwMS. Is a standard duration (e.g. 30 minutes) appropriate for each patient and for every appointment? Could we improve the effectiveness of appointments by creating a loose agenda ahead of time to ensure that nothing is missed, and that both parties can better prepare? Can digital technologies assist patients and physicians ahead of appointments, including helping patients to understand information and share their questions ahead of time? And how can physicians better acknowledge and respond to questions from patients which arise during or after an appointment?

While shared decision making is clearly an important part of patient engagement, its success is reliant on effective patient–physician communication. Research has consistently indicated significant barriers to communication between HCPs and pwMS, with disconnects often present in terms of disease understanding, treatment expectations, and priorities within care [9, 26, 40]. For example, HCPs typically prioritise physical functioning, whereas pwMS place more emphasis on mental health domains [41–44]. Healthcare professionals have been shown to underestimate the impact of MS on their patients' physical and psychological health early in a rehabilitation programme, but less so at the end, suggesting that with improved contact and communication, patients' and HCPs' perceptions of disease impact can align [45].

Similarly, there is considerable evidence to support the view that improved patient–physician communication, patient-centred care, and shared decision making are associated with increased patient satisfaction and empowerment, less decision conflict, less treatment non-compliance, less medical litigation, and a stronger patient–physician alliance [10, 27, 46, 47]. Unsurprisingly, patient understanding of the MS disease process enhances medication adherence [30], and those MS patients who feel that their autonomy is supported are more likely to adhere to medication regimens [28].

It is far from clear whether shared decision making is the correct option for every patient,

every time. It is also important to remember that communication and engagement isn't always a neurologist-led process. Nurses, physiotherapists, occupational therapists, and other members of the healthcare team can be equally, or more, important facilitators of patient communication. It is essential that there is good communication among these different members of the healthcare team and that they are sharing their unique insights with one another. Regardless of how much autonomy and involvement each patient prefers, there should be a clear and shared understanding of the rationale for treatment choices and of the patient's perspective among all those involved in the care of the patient.

It was noted that the MS in the 21st Century Steering Group is considering these issues and that, by studying the existing literature [27], and with the support and feedback of the broader MS community, it is developing tools and solutions to enhance patient–physician communication and relationships.

NAVIGATING THE NEW FRONTIER

In this debate, the speakers presented different perspectives regarding the extent of patient engagement in shared decision making, providing explanation and reflection on why this might vary for different patients and how it could best be optimised. There was a great deal of lively debate with the audience, with members making many useful contributions. This may have been the first time that many of those attending had heard the value of patient engagement being debated by a patient advocate and HCPs. There was broad agreement that the authentic patient voice needs to be heard more; there should be more presentations on this subject at major conferences and more publications produced in genuine collaboration with patients. MS in the 21st Century offers a model for patient involvement, and this debate demonstrates what can be achieved by inclusion, commitment, planning, and a willingness to address difficult issues. It is hoped that this debate provides reinforcement for the value of well-considered patient centricity in clinical

practice. The MS in the 21st Century Steering Group is currently developing communication tools, based on collected survey data, to optimise routine healthcare consultations for pwMS, which will be available in the near future.

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