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Unmet needs, burden of treatment, and patient engagement in multiple sclerosis: A combined perspective from the MS in the 21st Century Steering Group

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ABSTRACT

Background: Patient engagement is vital in multiple sclerosis (MS) in order to optimise outcomes for patients, society and healthcare systems. It is essential to involve all stakeholders in potential solutions, working in a multidisciplinary way to ensure that people with MS (PwMS) are included in shared decision-making and disease management. To start this process, a collaborative, open environment between PwMS and healthcare professionals (HCPs) is required so that similarities and disparities in the perception of key areas in patient care and unmet needs can be identified. With this patient-centred approach in mind, in 2016 the MS in the 21st Century Steering Group formed a unique collaboration to include PwMS in the Steering Group to provide a platform for the patient voice.

Methods: The MS in the 21st Century initiative set out to foster engagement through a series of open-forum joint workshops. The aims of these workshops were: to identify similarities and disparities in the perception and

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¹ New patient members who joined the Steering Group in 2016.

prioritisation in three key areas (unmet needs, the treatment burden in MS, and factors that impact patient engagement), and to provide practical advice on how the gaps in perception and understanding in these key areas could be bridged.

Results: Combined practical advice and direction are provided here as eight actions: 1. Improve communication to raise the quality of HCP–patient interaction and optimise the limited time available for consultations. 2. Heighten the awareness of ‘hidden’ disease symptoms and how these can be managed. 3. Improve the dialogue surrounding the benefit versus risk issues of therapies to help patients become fully informed and active participants in their healthcare decisions. 4. Provide accurate, lucid information in an easily accessible format from reliable sources. 5. Encourage HCPs and multidisciplinary teams to acquire and share new knowledge and information among their teams and with PwMS. 6. Foster greater understanding and awareness of challenges faced by PwMS and HCPs in treating MS. 7. Collaborate to develop local education, communication and patient-engagement initiatives. 8. Motivate PwMS to become advocates for self-management in MS care.

Conclusion: Our study of PwMS and HCPs in the MS in the 21st Century initiative has highlighted eight practical actions. These actions identify how differences and gaps in unmet needs, treatment burden, and patient engagement between PwMS and HCPs can be bridged to improve MS disease management. Of particular interest now are patient-centred educational resources that can be used during time-limited consultations to enhance understanding of disease and improve communication. Actively bridging these gaps in a joint approach enables PwMS to take part in shared decision-making; with improved communication and reliable information, patients can make informed decisions with their HCPs, as part of their own personalised disease management.

1. Introduction

The Multiple Sclerosis in the 21st Century initiative, established in 2011 and led by a Steering Group of international experts involved in the care and management of people with multiple sclerosis (PwMS), is committed to improving the standard of care for PwMS internationally (Box 1). In its 2012 consensus statement, the Steering Group identified the need for a better understanding of the unmet needs of PwMS and healthcare professionals (HCPs) in an effort to optimise disease management and improve patient outcomes (Rieckmann et al., 2013). One of the strategies put forward to achieve this goal, was to seek to understand and overcome the barriers of patient engagement in multiple sclerosis (MS) (Rieckmann et al., 2015).

It is essential to involve all stakeholders in potential solutions, working in a multidisciplinary way to ensure that PwMS can participate appropriately in their care (Rieckmann et al., 2015). Critically, adding the perspective of patients to that of their HCPs is essential for optimising care (Golla et al., 2012). While a shared decision-making approach in patient-centred care has been the focus of recent publications in MS (Ballesteros et al., 2017; Col et al., 2017; Colligan et al., 2017), it is still not as well developed as it is in other therapeutic areas, such as in the community of people living with human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS).

The achievements of people living with HIV/AIDS were held in high regard by both the HCPs and PwMS in the collaborative group. These achievements included persuading governments and societies to change their approach to the AIDS epidemic, helping negotiate reductions in

treatment costs with pharmaceutical companies, influencing how people with HIV were treated, and, through education, helping to reverse the stigma associated with the disease.

People living with HIV/AIDS also developed the Denver Principles (Anon, 1983), which called for a new relationship between people with AIDS, their healthcare providers, and society. They demanded that physicians perceive their patients as ‘whole people’, who should receive ‘accurate information’. Patient engagement and action has not only had an impact on the way HIV is managed today, but was also instrumental in driving local, domestic and international public health policy-making (Wright, 2013). These principles stated that equal weight should be given to patients’ and HCPs’ opinions regarding care; this revolutionary viewpoint continues to influence today’s healthcare approaches.

In line with the early views of HIV/AIDS patients and advocates, both PwMS and HCPs believe that collaborative interactions are required to fully understand and address the complex issues involved in MS, and to improve future care; a collective patient–HCP voice is a positive and powerful one. Although a patient-centred approach in MS has started to emerge in the literature (Ballesteros et al., 2017; Col et al., 2017; Colligan et al., 2017) there is still a lack of recognition of the importance of a shared PwMS–HCP perspective in MS care (Tintoré et al., 2016).

With this patient-centred approach in mind, in 2016 the MS in the 21st Century Steering Group formed a unique collaboration to include PwMS in the group. Using a series of open-forum workshops attended by this newly formed joint Steering Group, the participants set out to foster collaboration and explore differences in the way HCPs and PwMS

Box 1

The MS in the 21st Century initiative.

Members of the Steering Group include: 14 HCPs (including neurologists, a neuropsychologist, a health economist, an MS nurse, an MS rehabilitation specialist, and patient advocacy group representatives) and 11 PwMS.

The group meets regularly to discuss the creation of programmes and awareness to achieve the following objectives:

- to improve communication between patients and HCPs through joint education and interaction
- to improve awareness of and access to treatment and care through: specialists (neurologists), other HCPs and the wider healthcare team, and specialist services (including physiotherapy, rehabilitation and counselling)
- to improve provision/access to information by: providing high-quality information from credible sources, increasing public awareness of MS, and focusing on e-medicine and e-education
- to promote patient activation and self-management by: highlighting the significance and benefits of self-management, empowering patients through education and communication, and improving the social well-being and integration of MS patients.

Abbreviations: HCPs, healthcare professionals; MS, multiple sclerosis; PwMS, people with MS.

define and prioritise areas of greatest unmet need in MS. The topics discussed in the workshops included: unmet needs in disease management, the treatment burden in MS, and factors that impact on successful patient engagement. The group proposed that if differences exist in the perception and prioritisation of these issues, then shared decision-making, and ultimately true patient-centred care, will be difficult to achieve.

2. Methods

In 2016, 11 PwMS were invited to join the MS in the 21st Century Steering Group. Participants were chosen to include a mix of gender and age at varying stages of disease: newly-diagnosed MS, primary progressive MS (PPMS), and relapsing remitting MS (RRMS), and were drawn from different European countries and the USA. These PwMS agreed to take part in discussions, and be involved in the identification of practical advice for the future.

During a joint meeting with the HCPs in March 2016, the PwMS and HCPs participated in separate but concurrent workshops to discuss their perception of unmet needs, the treatment burden in MS, and factors that affect patient engagement. The aim of these parallel workshops was for each group to identify the key issues from their perspective (i.e. that of either HCP or patient) for each of the three discussion topics. The groups were asked to prioritise their results for each of the three topics in terms of the perceived importance to the improvement of care and patient outcomes. The results of the parallel workshops were shared and reviewed by both groups.

A subsequent joint workshop, attended by both groups, was designed to share findings, and discuss disparities and similarities in the results. All workshops, chaired by members of the MS in the 21st Century initiative and facilitated by professional moderators, were designed as open-forum workshops to encourage candid discussion among all participants.

A final workshop was held in September 2016 to discuss and confirm actions based on the issues identified in the previous workshops. This workshop was comprised of the same members who had taken part in the previous workshops (11 PwMS and 10 HCPs), attending either in person or via teleconference. From the results of these discussions, the joint group outlined practical advice and direction for how differences and gaps could be bridged by the wider MS community.

3. Results

Key outcomes from the workshops to identify disparities in perceptions and priorities of unmet needs, treatment burden, and patient engagement between the PwMS and HCP groups are presented below. Practical advice and direction from this initial collaboration is covered in [Section 4](#).

3.1. Topic 1: unmet needs in disease management

The similarities and disparities between the HCP and PwMS groups in the perception and prioritisation of key unmet needs in MS are presented in [Table 1](#).

Five main areas were identified within this topic: symptom management, access to treatment and reimbursement, personalised care, education and communication, and resources and information. Both groups identified 'a cure for MS' as the single greatest unmet need.

One particular unmet need for PwMS was the difficulty in communicating the invisible/'hidden' symptoms of MS that are hard to detect and monitor during standard neurological consultations. Although HCPs acknowledged the impact of these hidden symptoms, they considered symptomatic treatment and disease progression to be more significant than hidden symptoms. PwMS also considered that their changing practical needs relating to disease disability and quality of life (QoL), such as social care and employment issues, were not

consistently being met; these particular aspects of care were not identified by HCPs as a high priority.

HCPs identified the inability to offer specific therapies due to local treatment policies and high costs as an unmet need, and this was mirrored by the identification by the PwMS of a 'reluctance' on the part of HCPs to prescribe particular therapies. PwMS reported disparities in reimbursement policies in different countries, resulting in a barrier to personalised therapy. Time constraints was another issue raised by HCPs and PwMS; both groups were dissatisfied with the limited time available for clinical consultations, and acknowledged that this impacted on the ability of HCPs to discuss the disease and treatment options with patients. Both groups acknowledged the need for additional research into the impact of current therapies on QoL outcomes for PwMS, and the need to raise public awareness and understanding of MS to reduce prejudice and discrimination.

3.2. Topic 2: burden of treatment in MS

Similarities and disparities between the HCP and PwMS groups in the perception and prioritisation of key factors affecting the treatment burden in MS are presented in [Table 2](#). Three main areas were identified within this topic: risk versus benefit of MS therapies; treatment decisions; and compliance, adherence and monitoring.

From a PwMS perspective, it appeared that HCPs focus on the negative aspects of treatment (risk and potential adverse effects), rather than on the positive aspects (impact on disease progression, effect on symptoms). Conversely, HCPs reported apprehension over the level of risk patients were willing to consent to in relation to their therapy. Although anxiety about side effects with respect to therapy escalation was a shared concern for both HCPs and PwMS, this translated into hesitancy on the part of HCPs to escalate treatment. Both groups acknowledged that adherence to treatment was an issue, but for different reasons: for PwMS, the complexity of treatment added to the adherence burden; whereas for HCPs, patient adherence issues were due to the side effects of treatment.

HCPs identified the issue of PwMS not engaging in, or taking responsibility for, their disease management. Both groups believed that a mutually respectful, shared decision-making approach was necessary to enable both HCPs and PwMS to take responsibility for disease management.

3.3. Topic 3: patient engagement

The perception and prioritisation of key factors affecting patient engagement in MS are presented as a joint perspective agreed by both the HCPs and PwMS. HCPs and PwMS believed that the adoption by HCPs of a holistic approach during consultations was critical to patient engagement, and had a direct influence on how patients engaged with their HCPs. The three principal factors that were considered to have the most positive impact on patient engagement were: technology (electronic healthcare, electronic tools and resources); education (informed and supportive HCPs, access to information, patient-driven information); and support and involvement within society (peer support and social activities). For those in the PwMS group who had significant mobility issues that made engaging in society difficult, technology and the internet enabled peer support, reducing feelings of isolation.

HCPs and PwMS thought that factors that negatively affected patient engagement included lack of time with HCPs, the public image of MS (including misconceptions about MS), and a lack of access to high-quality information (lack of reliable resources, information that is out of date) ([Reen et al., 2017a](#)).

The negative impact of MS stereotypes on daily living was highlighted by newly-diagnosed patients in the PwMS group, for whom an overwhelming amount of inappropriate and inaccurate information affected their motivation towards patient engagement. A particular issue raised by HCPs and PwMS was that employment and staying part

Table 1
Similarities and disparities between HCPs and PwMS in the perception and prioritisation of key unmet needs in MS.

HCPs	PwMS	Similarities and disparities
<p>Symptom management</p> <ul style="list-style-type: none"> ● A cure for MS ● Symptomatic treatment and disease progression ● A lack of treatments available to manage progressive MS and the symptomatic aspects of the disease 	<ul style="list-style-type: none"> ● A cure for MS ● A lack of advances in the recognition and treatment of MS disease progression ● Invisible/‘hidden’ symptoms and mental health aspects of MS were difficult for PwMS to communicate, as well as being difficult to monitor and detect during neurological consultations ● Currently available therapies and approaches were not being used to address invisible/‘hidden’ symptoms due to a lack of recognition by HCPs ● Practical needs, not just clinical symptoms, relating to disease disability and QoL were not being met 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ both HCPs and PwMS recognised the need for a cure for MS and a lack of treatments/advances to manage disease progression ● Disparities: <ul style="list-style-type: none"> ○ PwMS placed a greater emphasis than HCPs on hidden symptoms, the mental health aspects of MS, and management of these symptoms ○ HCPs considered symptomatic treatment to be more important than hidden symptoms ○ The practical needs of PwMS were important to patients but were not identified as a pressing requirement by HCPs
<p>Access to treatment and reimbursement</p> <ul style="list-style-type: none"> ● Access to appropriate care is critical; inability to offer specific therapies due to local treatment stipulations/high treatment costs hinders care ● Need for more research into the impact of current therapies on QoL outcomes ● Perception that PwMS prefer not to discuss risks of treatment ● Lack of, or delay in, reimbursement for MS treatments, can slow the uptake of innovations ● Time spent counselling and providing information is often not reimbursed 	<ul style="list-style-type: none"> ● Lack of access to treatment and treatment support ● Reluctance on the part of some HCPs to prescribe particular therapies ● Lack of awareness of specific therapies/latest therapeutic options among some HCPs ● Need for more research into the impact of current therapies on QoL outcomes ● HCPs tend to spend too much time focusing on the risks of treatment, whereas PwMS want to discuss both risks and benefits ● More stakeholders need to be educated about the burden of MS to individuals so that they have a better understanding of the impact of reimbursement constraints 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ Both HCPs and PwMS acknowledged that access to appropriate treatment/care is important ○ Both groups recognised the need for more research into the impact of current therapies on QoL outcomes ● Disparities: <ul style="list-style-type: none"> ○ PwMS believed there was a lack of awareness of specific therapies/reluctance to prescribe certain therapies among HCPs; in turn, some HCPs were frustrated by not being able to offer specific therapies due to local restrictions ○ PwMS maintain that HCPs spend more time focusing on the risks of treatment ○ HCPs were focused on cost issues, reimbursement (including activities that were not reimbursed), and the complexity of this system ○ PwMS were focused on the impact that reimbursement constraints actually had on their day-to-day living ○ HCPs believe that PwMS did not want to discuss the risks of treatment ○ PwMS did want to discuss the risks of treatment to some extent, but preferred to discuss the benefits of treatment
<p>Personalised care</p> <ul style="list-style-type: none"> ● Professional training needs to offer more information on the provision of personalised and holistic care ● Time to communicate with PwMS and the multidisciplinary teams about the best and most appropriate options for each individual is limited 	<ul style="list-style-type: none"> ● Attention to personalised care needs greater time and resources in many healthcare systems ● Acknowledgement that no two PwMS have the same experience of the disease ● Dissatisfaction with the limited time available for clinical consultations ● Specific priorities are not consistently addressed 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ Both groups acknowledged that investment in resources is needed to fully achieve personalised care ○ Both HCPs and PwMS thought that the lack of time available during patient and HCP communication/clinical consultations was insufficient ● Disparities: <ul style="list-style-type: none"> ○ HCPs also believed that lack of time was an issue for multidisciplinary teams trying to determine the best options for the management of individual patients ○ PwMS considered that their priorities were not necessarily addressed during consultations; this point was not mentioned by HCPs
<p>Education and communication</p> <ul style="list-style-type: none"> ● Professional education and understanding of the needs of PwMS requires improvement ● Improved communication with PwMS regarding complex disease issues such as progression is important ● A lack of public awareness should be addressed through education and communication to dispel misconceptions about MS and reduce prejudice and discrimination in the workplace 	<ul style="list-style-type: none"> ● The HCP–PwMS relationship was deemed central to achieving optimal care ● Greater education for HCPs about hidden symptoms would help them to see the ‘whole patient’; this education should begin during the early part of training to reinforce the need to treat patients holistically ● HCPs do not fully understand what is most important to PwMS ● PwMS expressed the view that the lack of public awareness should be addressed through education and communication to dispel misconceptions about MS and reduce prejudice and discrimination in the workplace 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ PwMS recognised the importance of the HCP–PwMS relationship, and HCPs acknowledged that more can be done to improve the communication of complex issues to PwMS ○ Both groups highlighted the lack of public awareness, misconceptions and prejudice surrounding MS ○ Both HCPs and PwMS recognised that more can be done to improve the understanding of and education about MS and PwMS ● Disparities: <ul style="list-style-type: none"> ○ PwMS generally thought that HCPs did not understand what is important to them (i.e. HCPs adopted a ‘one size fits all’ approach) ○ PwMS specifically mentioned the need to educate HCPs about hidden symptoms and holistic treatment
<p>Resources and information</p> <ul style="list-style-type: none"> ● Information for patients needs to come from vetted and reliable sources 	<ul style="list-style-type: none"> ● PwMS have individual information needs 	<ul style="list-style-type: none"> ● Similarities:

(continued on next page)

Table 1 (continued)

HCPs	PwMS	Similarities and disparities
<ul style="list-style-type: none"> ● The complexity of claims and the time and resources needed to process reimbursement hinders treatment options 	<ul style="list-style-type: none"> ● Educational resources often lack disease information, with little or no consideration of specific disease states ● Lack of resources limits access to treatments and supporting services 	<ul style="list-style-type: none"> ○ Both groups acknowledged the need for better quality resources and information ● Disparities: <ul style="list-style-type: none"> ○ PwMS expressed the need for more personalised information and resources specific to different stages of the disease

Abbreviations: HCPs, healthcare professionals; MS, multiple sclerosis; PwMS, people with MS; QoL, quality of life.

of society was not covered in a typical consultation. Both HCPs and PwMS expressed the view that the lack of patient support in this area had the potential for patients to become socially isolated. HCPs and PwMS considered that the lack of overall support – including social, employment, family and legal support – had a negative impact on patient engagement.

4. Discussion

A number of key outcomes were highlighted in the workshops identifying disparities in the perception and prioritisation of unmet needs, treatment burden, and patient engagement. The differences, and the underlying reasons for them, need to be addressed before HCPs and PwMS can truly engage in the shared decision-making process. Both groups need to place equal importance on certain key outcomes to enable the process of patient engagement and shared decision-making that will ultimately lead to patient satisfaction and best patient care. PwMS need to be receptive to ‘highest priority’ issues from the HCP perspective, and HCPs need to consider how an acknowledgement of

PwMS-specific and individual concerns will enhance communication.

Although advances in medicine, technology and healthcare services offer improved clinical outcomes and QoL, there is also an increasing reliance on patients’ skills and motivation to optimise all the outcome benefits available. The consequences of patients not engaging with their own healthcare are, not surprisingly, borne most heavily by the patients themselves and their families, and include emotional, physical, social and financial implications (Rieckmann et al., 2015). Patients have better health outcomes when involved in their own healthcare; motivated patients show improved treatment adherence, reduced risk factors and improved health outcomes (Rieckmann et al., 2015; Tintoré et al., 2016). A shared decision-making approach between HCPs and PwMS is essential for patient-centred care.

From the key outcomes, HCPs and PwMS reached agreement on combined practical advice, which is presented in Section 4.1 as eight practical actions. These opinions and actions were elicited from a representative but limited number of HCPs and PwMS. A current focus for the Steering Group is to validate these findings with a larger and broader group of HCPs and PwMS.

Table 2

Similarities and disparities between HCPs and PwMS in the perception and prioritisation of key factors affecting treatment burden in MS.

HCPs	PwMS	Similarities and disparities
<p>Risk versus benefit of MS therapies</p> <ul style="list-style-type: none"> ● Level of risk of MS therapies that patients were willing to accept was a cause for concern among HCPs ● More patient support was needed to understand the concept of risk and to accept the nature of the risk posed by different therapies ● HCP and patient anxiety about treatment side effects may result in a reluctance to escalate treatment – possibly due to responsibility and liability concerns 	<ul style="list-style-type: none"> ● HCPs focus more on the risk than the benefit of treatments ● More information on the benefits of new treatments rather than focusing on risks ● Patient anxiety related to side effects results in neurologist hesitancy to escalate treatment 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ Both HCPs and PwMS expressed anxiety about side effects with respect to therapy escalation ● Disparities: <ul style="list-style-type: none"> ○ HCPs believed that PwMS did not appreciate the concept of risk, and possibly the side effects of treatment ○ PwMS considered that HCPs focused on the negative aspects of treatment (risk and potential adverse effects) rather than on the benefits of new treatments
<p>Treatment decisions</p> <ul style="list-style-type: none"> ● Lack of time and general access to the medical team is a treatment limitation ● A lack of access to disease-modifying treatments ● Irregular review monitoring with long waiting times ● Geography-related inequality in treatment options ● Need for novel treatments 	<ul style="list-style-type: none"> ● Concern about the practical implications of treatment and effects on QoL ● Some treatments carry a high financial burden ● Lack of reimbursement can lead to delays in treatment and risks inappropriate or suboptimal treatment ● Need for new and novel treatments 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ Novel treatment choices were welcomed by both HCPs and PwMS ● Disparities: <ul style="list-style-type: none"> ● HCPs were concerned with the barriers to effective treatment choice: limited time spent with patients, long waiting times, lack of access to medical teams and certain treatments ● PwMS placed emphasis on the practical implications of treatment and how it affected their QoL.
<p>Compliance, adherence and monitoring</p> <ul style="list-style-type: none"> ● Need for frequent and extensive disease and treatment monitoring can affect compliance ● Side effects of treatment were important for both initiation and adherence; irregular monitoring or long waiting times caused suboptimal side-effect monitoring 	<ul style="list-style-type: none"> ● The complexity of treatment adds to the adherence burden ● HCPs provide an inadequate explanation of the treatment options ● Treatment achievements or successes were often overlooked ● Side-effect management needs to be better supported 	<ul style="list-style-type: none"> ● Similarities: <ul style="list-style-type: none"> ○ Both groups acknowledged adherence to treatment was an issue ● Disparities: <ul style="list-style-type: none"> ○ PwMS thought that side-effect management was often poorly supported; but HCPs were aware of this and cited that irregular monitoring/suboptimal monitoring could contribute to this ○ PwMS placed importance on treatment options being explained and treatment achievements being acknowledged; these points were not mentioned by HCPs

Abbreviations: HCPs, healthcare professionals; MS, multiple sclerosis; PwMS, people with MS; QoL, quality of life.

4.1. Practical advice and direction for action

4.1.1. Improve communication to raise the quality of HCP–patient interaction and optimise the limited time available for consultations

Enhanced communication with HCPs that includes appropriately pitched information, together with honesty and respect from both groups, was considered vital to optimising patient outcomes. There is a growing recognition of the value of effective communication and conflict-management skills (Ha and Longnecker, 2010), which is highlighted by the inclusion of communication-skills training as part of medical education in Europe and the USA (Hausberg et al., 2012). Due to limited time and resources, it is imperative that HCP–PwMS consultations and health service interactions are maximised through high-quality communication. In chronic diseases, improved HCP–patient communication has been associated with better treatment adherence, satisfaction, understanding and retention of information, and overall health outcomes (Kinsman et al., 2010; Reen et al., 2017b; Langdon et al., 2012).

4.1.2. Heighten the awareness of ‘hidden’ disease symptoms and how these can be managed

Symptom-free disease should be the current goal of treatment, although it was evident from the results that a greater appreciation of the impact of invisible/‘hidden’ symptoms is required in order to have a positive impact on the QoL of PwMS. Hard-to-measure outcomes or ‘hidden’ symptoms continue to receive little attention in disease management, and this is corroborated in the literature (Le Fort et al., 2011; Mehr and Zimmerman, 2015). Hidden symptoms of fatigue, depression, cognition, sleep problems, sexual problems (Colombo et al., 2014; Learmonth et al., 2016; Marrie et al., 2017; Solari, 2014), and the mental and emotional impact of MS (Vickrey et al., 1999) continue to be unmet needs. An increased awareness of the impact of hidden symptoms, as well as of the mental health aspects, of MS could help to elicit positive change in addressing the unmet needs of PwMS.

4.1.3. Improve the dialogue surrounding the benefit versus risk issues of therapies to help patients become fully informed and active participants in their healthcare decisions

As the therapeutic landscape of MS evolves, a thorough evaluation of the potential risks and benefits of treatments is critical to decision-making. However, current evidence suggests that other factors should also be taken into account, including the natural history of untreated disease, monitoring capabilities, co-morbid illnesses, co-medications, patient preferences, attitudes, ability to adhere to medication, and patient expectations (Lugaresi et al., 2013; Saposnik et al., 2016).

The benefit versus risk profile of any treatment strategy is a time-consuming and complicated task, and depends on the risk-taking tendencies of patients and their HCPs. A lower level of safety concern about disease-modifying drugs among PwMS compared with HCPs was highlighted in a recent focus-group study (Kremer et al., 2017). A greater depth of information on treatment risk/benefit has the potential to improve patient engagement and adherence, and reduce the perceived treatment burden (Lizán et al., 2014). It has been suggested that, in the event of HCPs and PwMS disagreeing about acceptable risk, PwMS may be willing to accept greater levels of risk in exchange for therapeutic benefit, e.g. if treatment allows them to continue to walk (Reed Johnson et al., 2009). A lack of information regarding risks and desired outcomes may also increase the stress of treatment decisions for the patient (Barre et al., 2015).

4.1.4. Provide accurate, lucid information in an easily accessible format from reliable sources

The Steering Group’s aspiration is for all PwMS to have access to accurate, up-to-date, reliable and comprehensible information that will help empower them and allow them to feel better placed to make treatment decisions. Educational resources should also be specific,

disease-stage information, user-friendly, and in an accessible format for PwMS, their families and carers. Inappropriate, inaccurate or overwhelming information negatively affects the motivation of PwMS, preventing full engagement with their disease, treatment and health-care needs. Studies suggest that PwMS frequently report difficulties in locating personally relevant information on the internet. The higher educational level required to understand health information worsens health inequalities, preventing full participation in decision-making (Moccia et al., 2016).

4.1.5. Encourage HCP and multidisciplinary teams to acquire and share new knowledge and information among their teams and with PwMS

Recent advances in the field of MS, largely driven by progress in diagnosis, MS neurobiology, and the development of new treatments, have been identified (Mehr and Zimmerman, 2015). However, such advances can add to the disease and treatment burden experienced by PwMS and HCPs. Rapid advances in treatment options may lead to frustration when HCPs are unaware of the latest data, or do not have the capacity to communicate relevant information to patients. The growing financial constraints placed on healthcare services, and the lack of reimbursement in some healthcare systems, adds to this burden by limiting the time available for, or the number of, consultations.

A lack of resources was deemed to be a negative influence on the HCP–PwMS relationship, reducing the quality of interaction. This observation aligns with similar findings by others that highlight the importance of adequate consultation time and access to the general medical team in addressing disease and treatment burden (Le Fort et al., 2011).

4.1.6. Foster greater understanding and awareness of the challenges faced by PwMS and HCPs in treating MS

Communication and education were considered essential for raising awareness and understanding of MS and dispelling misconceptions about the disease. Misconceptions about MS can hinder acceptance of the diagnosis in new PwMS (Fallahi-Khoshknab et al., 2014) and can cause health anxiety in all PwMS, with a subsequent impact on QoL, perception of symptoms (Hayter et al., 2016), and an increased risk of depression (Santoro et al., 2016). Conversely, positive personal perceptions about MS, such as a perception of treatment control or a realistic MS timeline perspective, are more strongly correlated with disease self-management than are objective clinical variables such as the severity, type and duration of MS (Wilski and Tasiemski, 2016).

Education and an increased awareness of MS among the general public may help PwMS to feel less excluded from society, as well as potentially lead to better healthcare and, ultimately, positively influence reimbursement/funding decisions in healthcare systems.

Some of the basic needs of PwMS that were identified as unfulfilled almost two decades ago, such as a holistic approach to care, continue to remain unmet today (Colombo et al., 2014; Learmonth et al., 2016; Solari, 2014). The ongoing reductions in healthcare budgets further preclude the provision of the personalised care that is critical to PwMS. Adopting a shared approach that considers the views of both PwMS and HCPs can be more effective in achieving better outcomes in MS care by fostering a truly co-operative and holistic understanding of the issues faced by PwMS.

4.1.7. Collaborate to develop ‘joint’ local education, communication and patient-engagement initiatives

Although there are many examples of educational and awareness activities designed and delivered for and by HCPs and PwMS as separate entities, there are few opportunities for the groups to interact, learn and communicate together outside the clinical setting. Such opportunities should be encouraged to foster better understanding and collaboration between the groups. A co-alliance of PwMS and HCPs enables the alignment of objectives, recognises the range of different patient needs, and solicits an inclusive view for the best way to resolve these

issues. Without collaboration, there is a risk that HCPs and PwMS will work at cross-purposes, and that resolution of issues will, at best, be delayed.

Involvement in society and engagement with community activities were considered key factors in promoting inclusion and motivating patients to further engage in their healthcare needs. The engagement of patients in their own healthcare has been described as the ‘blockbuster drug of the century’ (Rieckmann et al., 2015). From the early stages of this disease, PwMS are vulnerable to social exclusion; negative perceptions of the disease can also invoke prejudices and inequalities, and have a negative impact on employment opportunities (Oreja-Guevara et al., 2017). As disability worsens, the ability to work and interact socially becomes further restricted, meaning that efforts to enhance collaboration and develop a globalised MS community are therefore much needed.

4.1.8. Motivate PwMS to become advocates for self-management in MS care

The responsibility for PwMS to engage in their own health lies with everyone involved in their care as well as with the patients themselves. Harnessing this sense of responsibility towards self-management, at all levels, may be instrumental in motivating engagement (Rieckmann et al., 2015). A sense of responsibility may also be fostered by PwMS becoming patient-educators for other patients or medical professionals. This has been shown to be a rewarding and therapeutic experience, offering patients benefits such as raising their self-esteem and sense of empowerment, gaining new insights into their own issues, fostering a better understanding of the patient–doctor relationship and improving QoL (Rieckmann et al., 2015).

5. Conclusion

Our study of PwMS and HCPs in the MS in the 21st Century initiative has highlighted eight practical actions for the wider MS community. These actions identify how differences and gaps in unmet needs, treatment burden, and patient engagement between PwMS and HCPs can be bridged by improving MS disease management. Shared decision-making enables patients to make informed decisions with their HCPs as part of their own personalised disease management. Of particular interest now is the development of patient-centred educational resources that can be used during consultations to enhance disease understanding and improve communication between PwMS and their HCPs. This patient-centred approach not only allows patients to be more comfortable with the decisions they make, but enables active participation in self-care.

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