COMMENTARY

Perspectives from the Patient and the Healthcare Professional in Multiple Sclerosis: Social Media and Participatory Medicine

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ABSTRACT

When faced with a diagnosis of multiple sclerosis (MS), patients often turn to the Internet and social media to find support groups, read about the experiences of other people affected by MS and seek their advice, and research their condition and treatment options to discuss with their healthcare professionals (HCPs). Here, we examine the use of social media and the Internet among patients with MS, considering its impact on patient empowerment and patient participation in treatment decision-making and MS research. These themes are exemplified with first-hand experiences of the patient author. We also explore the impact of the Internet and social media on the management of patients from the perspective of HCPs, including new opportunities for HCPs to engage in

participatory medicine and to improve communication with and among patients. We consider both the benefits afforded to and the potential pitfalls faced by HCPs when interacting with their patients via these routes, and discuss potential concerns around privacy and confidentiality in the use of the Internet and social media in the clinical context. Communication online is driving the evolution of the patient–HCP relationship, and is empowering patients to participate more actively in the decision-making process relating to the provision of their health care.

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Keywords: Internet; Multiple sclerosis; Online; Participatory medicine; Patient voice; Shared decision-making; Social media; Web

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INTRODUCTION

Individuals receiving a diagnosis of multiple sclerosis (MS) face many life-altering challenges. However, over the last decade, improved access to high-quality information and the ability to share experiences with other MS patients through the Internet and social media have helped patients become more knowledgeable about their condition and about MS research, including their diagnosis, treatment options,

and clinical trials. This has allowed patients to manage their disease proactively and, in some cases, has afforded the opportunity to influence clinical research. As early as 2007, a survey of 2390 Americans with MS reported Internet use by 93% of participants (compared with 75% of the general population), of whom 53% indicated that it had helped them to become their own MS advocate [1]. As well as being widespread among patients, the use of social media among Western healthcare professionals (HCPs) has dramatically increased in recent years, rising from 42% of practicing physicians in 2010 [2] to almost 75% in 2013 [3]. Among HCPs, 65% use social media for professional reasons, mostly in professional networks and clinical practice, but also for informing and helping patients [4–6].

These developments have empowered patients to act more in partnership with their HCPs in determining what care they receive, shifting away from a traditionally passive role to an active, self-governing one, with participatory decision-making playing a key part in determining treatment [7]. In this article, we aim to explore the impact of virtually instant global access to information on the interaction between patients with MS, the HCPs who treat them, and the MS community. These interactions are examined in terms of participatory medicine, of the direction of MS research, of the sharing of experiences among patients, and of the privacy and ethical considerations when using social media and the Internet in healthcare communications.

METHODS

This article offers qualitative case study-based insights from the patient and HCP authors, both of whom are from North America. As in our accompanying article, which examines the impact of social media and the Internet on aspects of patient education, the HCP's perspective in this article is provided by an MS specialist, Daniel Kantor, MD, FAAN, Past President of the Florida Society of Neurology, President of the Medical Partnership 4 MS, Chief Medical Correspondent for MSWorld, and an active member of the Multiple Sclerosis Foundation's Medical Advisory Board and the

Multiple Sclerosis Association of America's Healthcare Advisory Council. The patient's perspective is provided by Jeri Burtchell, a clinical trials awareness activist, MS patient advocate, founder of Partners in Research, and Director of Patient Initiatives at HealthiVibe, LLC. These perspectives are drawn together, in the context of published research, by Jeremy Bright, a medical writer at Oxford PharmaGenesis with a special interest in MS. This article also includes some of Jeri's experiences since receiving an MS diagnosis in 1999, 3 months after the onset of symptoms.

The patient's perspective was provided as follows: a Novartis employee drafted a set of questions for use in a subsequent interview with the patient author (Jeri Burtchell). During the interview, Jeri's responses to these questions were recorded. Unedited and non-paraphrased quotes were taken directly from the recordings and used as required throughout the manuscript. The HCP's perspective was provided directly by the HCP author, Daniel Kantor. To the best of our knowledge, this "patient–HCP dyad" approach has not been used before to explore patient and HCP perspectives regarding the impact of the Internet and social media on the interaction between members of the MS community. Adopting this novel approach thus enabled us to gain detailed and direct insights into specific issues not previously reported.

The patient and HCP perspectives described in this article were provided by single individuals from the USA. As the insights yielded by this approach are specific to the authors' personal experiences, the generalizability of the findings may be limited as they may not be representative of those of the wider MS population and other HCPs. In order to minimize any bias, a separate literature search was conducted to identify relevant articles that contextualized the themes identified by both the patient and HCP authors. Supporting published references and online resources relating to Internet and social media use in MS were identified using MEDLINE and Google Scholar, with the search strings "multiple sclerosis [Title/Abstract] AND social media [Title/abstract]" and "multiple sclerosis [Title/Abstract] AND Internet [Title/Abstract]".

Compliance with Ethics Guidelines

This article does not contain any new studies with human or animal subjects performed by any of the authors.

OVERVIEW OF KEY FINDINGS

In exploring the impact that the Internet and social media have had on interactions between members of the MS community, Jeri and Dr. Kantor's perspectives could be grouped into four major themes: (1) participatory medicine and the changing face of patient–HCP interactions; (2) promoting and fostering MS research; (3) sharing experiences and interpersonal contact; and (4) privacy, confidentiality, and ethical considerations. In the following sections, we present Jeri and Dr. Kantor's views on each of these topics and contextualize them in terms of the available literature. Two further sections outlining the future potential of social media and concluding remarks from Jeri have also been included to provide additional information on this topic.

PARTICIPATORY MEDICINE: CHANGING FACE OF PATIENT–HCP INTERACTION

Participatory medicine has been defined as a model of cooperative health care that seeks to achieve active involvement by patients, HCPs, caregivers, and others across the continuum of care on all issues related to an individual's health [7, 8]. Participatory medicine is considered to be an ethical approach to care that may help to improve outcomes, reduce medical errors, increase patient satisfaction, and reduce the cost of care through partnership between patients and their HCPs [7, 8].

Patient's Perspective

In the traditional model of biomedical care (one of medical paternalism), HCPs hold the position of authority while patients assume a passive

role, following the instruction of their physicians with little input into the decision-making process. Jeri was diagnosed with MS in 1999, 3 months after the onset of symptoms. Below, Jeri recalls what little involvement she had regarding the treatment she would receive.

“At that second visit to my neurologist's office, when he gave me the bad news, we discussed all the available treatment options. They were all injectable drugs, only one of which was not an interferon. This was the drug my doctor chose for me. We didn't choose together because, in my eyes, he was the expert and knew best.”

Jeri would typically have three or four relapses annually for the first 7 years, and often had to use a walker or a wheelchair for months at a time. Despite asking if she could switch to a more effective treatment, her HCP said she should remain on her current therapy.

“When I asked my doctor about switching [treatment], I didn't understand why he thought my drug was working when I was having bona fide relapses requiring steroid use several times per year.”

“At the time there were only four MS drugs and I was taking the only one that wasn't an interferon. He insisted I stay on the therapy I'd been on all along, reassuring me that my MS would be 'so much worse' if I weren't taking it.”

“I had no idea that I could challenge my doctor, or even that I could find a new one. Since he was the only one in my town, I felt I had no choice. I was despondent that I was relapsing so often and felt like things might never get any better.”

Central to the success of participatory medicine is the dynamic between HCPs and patients. While physicians bring their training and clinical expertise, patients bring their life experiences, skills, and resilience, their deep investment in their long-term health, and a unique perspective on needs and priorities [9]. Effective patient–HCP partnerships build trust, help patients feel informed, in control, and empowered, and promote shared decision-

making in effective and time-efficient consultations [10, 11]. Seven years after her initial diagnosis, an opportunity arose for Jeri to engage with a different HCP.

“In 2006 my neurologist had a stroke and I was left without a doctor. I would wind up at my PCP’s [primary care physician’s] office every time I had MS symptoms and he finally convinced me in 2007 that I needed to see a new neurologist in a nearby city.”

Jeri discussed the advantages and disadvantages of different treatments with her new neurologist. The interaction followed a participatory model, and Jeri’s interaction with the online MS community helped her to become more assertive in the management of her care.

“I didn’t want to take one of the interferon medications (my only other option) due to the fear I’d developed based on the strong feelings my former neurologist had regarding them, and also from reading so much from patients online who shared their ‘flu-like symptoms’ and feeling miserable on the medication.”

“Before the Internet, when first diagnosed, I depended on my neurologist. His opinion was the final say about everything from use of steroids to physical therapy to which disease-modifying medicine I would use. The Internet empowered me as a patient to become informed about my condition, to consider my options and the opinions of others, and to take charge of managing my disease in the best possible way for me.”

HCP’s Perspective

Dr. Kantor highlighted how clear, two-way communication is vital to foster successful partnerships between patients and HCPs, something that is also described in the literature [10, 11]. In a US survey of patients who presented for the first time at an MS clinic between 2003 and 2005, 82% of individuals performed web-based searches in preparation for their initial consultation. Hence, it was perhaps surprising that only 36% of those who had gathered information before their first

appointment subsequently discussed it with their HCP [12]. This is especially surprising given that patients within the 2011 North American Research Committee on Multiple Sclerosis (NARCOMS) registry indicated that their most trusted information source was an HCP, with 98% of patients reporting that they trusted a physician “some” or “a lot” [13].

Dr. Kantor also noted how in recent years, the importance of shared decision-making in patient–HCP communication has gained increasing recognition, particularly for chronic diseases such as MS for which the treatments are not curative. Indeed, a German study found that between 2001 and 2007, 80% of patients with MS demanded autonomous roles in decisions relating to their treatment [14]. Given that use of social media has almost certainly led to a patient population that is well informed about current treatment options, it would be reasonable to expect that this has resulted in patients challenging their HCP’s prescribing recommendations more often and further influencing their practice patterns. Published evidence examining the effects that social media may have had on the shared decision-making process is scant, but this is an area where more research would be valuable.

Although HCPs generally welcome a well-informed patient base, given that a better understanding of treatment may lead to greater adherence and patient engagement, Dr. Kantor acknowledged that some HCPs may feel defensive when patients challenge their medical knowledge or recommendations. He explained that although modern medicine is much less paternalistic than it was several decades ago, the expectation that HCPs’ authority should be respected (if not revered) still lingers in some quarters.

Attempts have been made in the literature to quantify the influence of social media on the patient–HCP relationship, albeit not specifically relating to MS. In a multidisciplinary survey of 232 Brazilian HCPs carried out in 2011–2012, 57% thought use of the Internet helped the patient–HCP relationship, but 28% thought it interfered with it, and 16% felt it had a negative impact [15]. A small qualitative multidisciplinary survey of German HCPs, patients, and a

patient organization representative published in 2012 largely echoed these findings. Most patients from Germany continued to regard their HCP as the expert, but being a better-informed patient made the relationship with their HCP more balanced, with patients becoming more critical and interrogating recommendations made by their HCPs [16]. No German HCP reported feeling threatened or undermined by this shift in the relationship, but some noted that consultations could be prolonged when patients attended their consultation ready-armed with a self-diagnosis based on Internet research [16].

However, findings from UK and US articles have shown that with HCPs becoming increasingly burdened by non-face-to-face commitments (such as inordinate time spent obtaining prior authorizations), a more engaged and self-educated (social media-educated) patient base has the potential to help improve the efficiency of the delivery of care [4, 17, 18], perhaps by enabling patients to ask more informed questions about their disease, thus saving some of the time that HCPs need to commit to educating patients about their disease process and treatment options.

PROMOTING AND FOSTERING MULTIPLE SCLEROSIS RESEARCH

Patient's Perspective

Before the availability of the Internet, and even until quite recently, patients would probably have learnt about a trial of a new drug from newsletters (as Jeri did in 2006–2007), or from their HCP.

“I was still learning about MS from offline sources at this time and when I received a MOMENTUM magazine from the National MS Society talking about a new pill form of treatment still in clinical trials and recruiting, I decided to ask my new doctor about it. My new neurologist was Dr. Daniel Kantor who, at the time, was lead investigator for the TRANSFORMS trial at the University of Florida. At my first

appointment we discussed the pros and cons of being in a study, and we weighed the options.”

“So I took the informed consent home to read, and share with friends and family to get opinions on whether or not I should join.”

“I also tried to find anything online from a patient perspective about participating in a clinical trial. All I could find was from the research side.”

Jeri took the decision, which was at the time unusual, to blog her experience of participating in this trial.

“My blog would come to be widely accepted as the first start-to-finish blog of a clinical trial from a patient perspective. A pharmaceutical executive once dubbed me the ‘godmother of the intersection of social media and research’.”

US-based social media and websites (e.g., PatientsLikeMe) are now widely used by patients with MS not only to find information on clinical trials, such as how to participate in them and study results, but also to communicate their on-trial experiences [19–22]. Furthermore, this avenue of communication affords patients the opportunity to provide input on trial design. Indeed, this is also something Jeri has been actively involved in.

“Currently I work for HealthiVibe, LLC, a company focused on bringing the patient perspective to clinical trial design and patient-facing initiatives so our pharmaceutical clients can design studies and programs that are more meaningful and patient-friendly.”

Concerns have been raised in the literature that large numbers of patients interacting via social media during a clinical trial could have the unwanted consequence of breaking the blinding of a study [20]. Again, this was something that Jeri identified with and had also experienced directly.

“The question of possible unblinding due to patients finding each other via social

media has become a real issue. A few of us who remained in contact did reach out to each other once we'd been unblinded to see if the others knew. We were all correct in our suspicions. But we all agreed that regardless of having found each other, it's only natural to wonder which arm you are in and to guess—whether silently to yourself, or out loud to family, friends, or those on social media. Together with a handful of blog followers who had joined the clinical trial, I created a Yahoo! group to have a more private place for us to gather and commiserate. In order to gain access, members had to prove they were in the trial by sending me a photo of their medication bottle. While some people did want to talk about possible side effects and try to figure out if they were on the real drug or not, mostly we talked about normal things like family and jobs."

HCP's Perspective

There are several published examples of the successful use of social media to recruit participants to MS studies, including a US trial examining the adverse effects of switching treatment and a large Australian study assessing factors that may contribute to fatigue [20, 21, 23]. In 2012, the US Food and Drug Administration also approved a "crowdsourced" protocol for an MS trial that was developed with an online community of patients, HCPs, and researchers [22]. Dr. Kantor also noted that in addition to pharmaceutical company and MS patient advocacy websites that act as gateways to clinical trials, patients with MS write blogs that offer advice on accessing clinical trials, and MS community websites promote participation in studies (e.g., <http://partnersinresearch.org>, <http://mymsteam.com>) and encourage participants to share their research experience (<http://projectdreamnow.org>, <http://patientslikeme.com>). Indeed, in 2009 an online community of US patients with MS was used to develop a self-report questionnaire in order to quantify adherence and to identify any barriers to achieving adherence that are specific to MS

disease-modifying treatments [24]. Social media could also be used by patients for real-time reporting of adverse events [25].

SHARING EXPERIENCES AND INTERPERSONAL CONTACT

Patient's Perspective

Jeri was a frequent user of online forums, and as time progressed, she began to build up her own network of trusted members and online sources.

"After posting on forums for a while, I began to privately message other members and online relationships—some of which continue to this day—began. It was in this way that we developed a network of trusted sources within the larger MS forums, and we would share links to information, or other forums."

It is evident that social media provides an invaluable channel of communication and interaction for people with disabilities [26] and has the potential to relieve social isolation and improve quality of life by connecting patients to the wider world. For example, among individuals in the 2011 NARCOMS registry, 61% used the Internet for social networking [13]. The Multiple Sclerosis International Foundation (MSIF) 2014 global survey examining technology use and MS also revealed that social media was used for peer support and for building an MS community, with more than one-third (38%) keeping in touch with other people with MS [27]. Jeri found the "connecting" aspects of social media particularly valuable, and relationships within her network strengthened as a direct result of being able to connect with each other instantly.

"During the time I was blogging, I had my posts set up to automatically show up on Facebook and Twitter. Although I had used Facebook to some degree, I had never used Twitter very much."

"When I got a smartphone in 2011, however, I became even more involved in social media. The apps for Facebook,

Twitter, and LinkedIn allowed me to connect to others even when I wasn’t at my computer, which resulted in a much deeper, richer social media experience. I could share with others instantly instead of waiting to blog once I got home.”

“Because I had cultivated a group of friends whose opinions I trusted, the feedback was meaningful and almost always instant.”

Examples of the kinds of social networks that have been developed for patients with MS include <http://mymsteam.com>. This US forum was set up specifically to allow patients to talk to each other about the day-to-day realities of living with MS, sharing practical tips and personal experiences, as well as providing support and advice to each other on issues that can only be answered by someone living with the condition [28]. During a presentation at the 2015 conference of the European Committee for Research and Treatment in Multiple Sclerosis, it was noted how sharing experiences on social media helps patients feel less alone, giving them hope and providing an opportunity to talk about things they felt were too embarrassing or stressful to share with close friends and family (e.g., issues with incontinence) [29]. The Internet also provides opportunities to explore patients’ experiences of living with MS and of different treatment options, such as those in the MS in America study, as reported on the <http://MultipleSclerosis.net> website [30].

Social media has also transformed how patients and HCPs communicate with each other, especially in regions that have highly developed healthcare systems, such as Canada, Europe, Israel, and the USA. Traditionally, HCPs and patients with MS in these regions have communicated and exchanged information via face-to-face contact during clinic visits as part of routine follow-up. However, as more and more patients use computers and mobile electronic devices to access health-related information, they are also becoming more interested in using digital technologies to complement face-to-face communications with their HCPs [31, 32].

HCP’s Perspective

Rather than being spectators to their patients’ use of health-related information on the Internet and social media, Dr. Kantor outlined how HCPs have become involved in actively using these channels (a number of reasons that might motivate HCPs to have a social-media presence are summarized in Table 1) [33]. Studies have shown that social networks afford HCPs the opportunity to communicate with online patient communities, and share health messages that are likely to resonate with patients and be adopted by them [6], while simultaneously responding to their requests for accessible, interactive, two-way communication [34]. Evidence suggests that social media may also improve patient outcomes and reduce healthcare resource use [35]. Indeed, data from a 2015 systematic review and meta-analysis found that social networking site interventions in Australia, the UK, and the USA had a statistically significant positive effect on the promotion of health-related behavioral change [36].

Indeed, US HCPs may use social media, such as Twitter and Facebook, for the purposes of enhancing communication with their patients and the wider healthcare community, including providing patient education and disseminating public health information [37]. Across regions, the most widely used channels tend to be online communities that allow for catching up on the latest news and developments, and networking and communicating with colleagues on patient issues [5, 38]. With this in mind, MS HCPs could set up a Facebook page or Google+ circle specifically to distribute disease-based information and

Table 1 Reasons why physicians use social media [33]

To connect	To be challenged
To engage	To be supported
To inform	To lead
To reflect	To learn
To share	To inspire

guidance to patients, and to provide links to sites with other relevant information [4, 37]. Such platforms also provide an opportunity to post videos and newsletters and to conduct web-based seminars [6]. Institutions can play a valuable role in using social media as a vehicle for patient education, but as described in the accompanying article on patient education, institutional use of social media is not always directed in this way nor is it always managed by individuals with knowledge of patient needs in MS.

In terms of patient–HCP interaction, Dr. Kantor explained that there is a need to consider the differences between using social media to disseminate information to large groups of patients and using it to interact directly with an individual patient. Evidence suggests that the communication options offered by social media may help to promote efficient use of resources and staff time [4]. However, despite a rapid increase in its use, many HCPs are reluctant to incorporate social media into routine clinical practice owing to uncertainty surrounding ethical and legal obligations, public access [2, 3], data security, and privacy regulations (e.g., the Health Insurance Portability and Accountability Act), managing the expectations of social media-savvy patients, and the lack of reimbursement for time spent. Indeed, results from a survey of Australian HCPs published in 2015 revealed that 66% of respondents were hesitant to engage fully in communications with patients via social media [3]. Notably, 19–35% of US and Australian HCPs have received a “friend” request from a patient via a social networking site, although few respond [2, 3]. Few of the US HCPs reported sending a “friend” request to a patient or family member (1–5%) [2], although in a separate US study, some HCPs reported making a conscious decision to “friend” or connect with patients on social networks in an attempt to encourage engagement and to appear approachable [39].

PRIVACY, CONFIDENTIALITY, AND ETHICAL CONSIDERATIONS

Patient’s Perspective

Maintaining patient confidentiality and privacy is an important issue when considering social

media in healthcare settings [40], and this may influence how patients engage with and benefit from social media. This was a particular concern for Jeri.

“With more and more platforms becoming available for patients to connect, I believe security and privacy are being better addressed.”

“The privacy of Facebook groups was hard to understand for some at first. When their posts would appear in their own Newsfeed outside of the group, people became alarmed and raised the question of privacy with the group admins [administrators]. I believe nowadays Facebook users have a better understanding of how privacy works within groups. That’s not to say there aren’t strong suspicions among patient members of these groups that there are ‘plants’ who are members of pharmaceutical companies trying either to learn about the purpose of any given group, or to correct misinformation about their product, or even to speak badly of a competitor’s drug. The group admins try to stay on top of these types of accounts, researching other activity to gauge whether or not the account is that of a real patient.”

HCP’s Perspective

Social media raises privacy issues for HCPs as well as for patients [40]. As with all patient–HCP contact, patient confidentiality is paramount both ethically and legally (e.g., policies for securing the privacy of individually identifiable health information are enshrined in the US Health Insurance Portability and Accountability Act) [41], and confidentiality breaches can arise if fragments of information can be assembled from different sources. It is important to remember that certain information can be accessed freely by everyone online; therefore, prudence dictates that the most secure privacy settings should be selected when communicating with patients and that these settings are updated regularly [4, 42, 43]. Although social media provides a platform that could

dramatically change the way that HCPs engage with patients, the boundary between HCPs’ private and professional lives can become blurred when using social media [44]. In the UK and USA, guidelines exist to help HCPs to optimize their use of social media, while ensuring that professional and legal obligations are met and that patients receive appropriate protection [42, 43, 45]. Dr. Kantor noted that these guidelines highlight the need to maintain professionalism, patient confidentiality, and appropriate patient–HCP relationships, as well as to be aware of legal issues (e.g., defamation, as will be discussed) and conflicts of interest (Table 2). He also pointed out that it is essential to apply the same medical values and principles during online interactions as when meeting a

Table 2 Steps healthcare professionals can take to avoid some pitfalls of using social media [42–45]

Area	Suggested actions
Professionalism	Apply medical ethical values and principles at all times
	Protect your online image
	Be polite and respectful
	Be aware that social media can be monitored by others
	Avoid defamatory comments
	Disclose any conflicts of interest
Patient confidentiality	Patient confidentiality is an ethical and legal obligation
	Limit access to online content
	Use the most stringent privacy settings available
	Be careful giving individual patients medical advice online
Patient–HCP relationship	Maintain professional boundaries
	Avoid engaging in non-professional relationships
	Be cautious of accepting “friend” requests

HCP healthcare professional

patient face-to-face. Although HCPs should be compassionate and engage with patients, it is imperative to maintain professional boundaries.

The UK and US guidelines recommend that HCPs should not accept “friend” requests; however, the advice is inconsistent [42, 43, 45]. In addition, defamation law applies to interactions via social media, so derogatory or personal comments should be avoided [42, 43]. It is also important that HCPs are mindful of their online image and how it might reflect on them professionally: social media activity is often monitored by others, including the press, especially in public forums and on micro-blogging sites such as Twitter [42, 43]. Although social media provides the opportunity to share expertise and information, caution should be exercised when providing personal advice online [43], and responding to questions sent via social media could expose HCPs to legal action [6]. It is also important to consider that users with limited social media experience are more likely to make mistakes than those accustomed to using it. Such mistakes could have severe consequences if patient privacy is unwittingly breached [46].

FUTURE POTENTIAL OF SOCIAL MEDIA

Social media is helping patients with MS to become more informed about their diagnosis, and thus it is encouraging them to take greater responsibility for their own health care. These “e-patients” are individuals who are equipped, enabled, empowered, and engaged in their own health and healthcare decisions [8]. They are changing the relationships among HCPs and patients and demanding a more equal partnership, with shared decision-making and responsibility. Social media will continue to drive the cooperative approach of participatory medicine, with patients actively participating alongside HCPs in all aspects of their own health care, with the ultimate aim of improving outcomes and patient satisfaction [8]. In the future, interfacing with electronic medical records and monitoring disease management in real time will be made possible using mobile electronic devices and the Internet. The role of social

media in these developments is unclear. Current guidelines recommend that social media is not used for providing medical advice to individual patients, so wholesale replacement of direct patient–HCP interaction seems unlikely.

FINAL THOUGHTS: “HOW SOCIAL MEDIA HAS CHANGED ME AS A PATIENT”

Access to the Internet and interaction via social media has broadened horizons for patients, empowering them not only in managing their own treatment but also in helping and supporting others, and in contributing more actively to medical research. This is a sentiment echoed by Jeri.

“The Internet empowered me as a patient to become informed about my condition, to consider my options and the opinions of others, and to take charge of managing my disease in the best possible way for me. I realize everyone’s experience with MS and medications is different, but the Internet has been the single most powerful influence in my arsenal of tools to combat this disease.”

“I use social media to meet others with MS, and to find ways to make a difference and have a positive impact. Staying connected in this way has given me hope for the future and has given my life purpose. It has made having MS be more of a conduit and less of a burden. Without the Internet and social media I am convinced I would be isolated, introverted, and miserable.”

CONCLUSIONS

As identified by Jeri and Dr. Kantor, and across different countries in the supporting literature, a wide range of benefits for MS participatory medicine can be gained from the targeted use of the Internet and social media. The rise of the e-patient—an informed and empowered individual who is actively involved in their own healthcare management—is challenging the

traditionally passive role that patients used to play. This change in behavior has made the HCP–patient relationship more of an equal partnership, with decision-making and responsibilities now shared between both parties. Use of these platforms also has potential to change dramatically the way HCPs engage with their patients and peers. However, there are a number of important privacy, confidentiality, and ethical issues that must be considered, which may limit certain use of these platforms, especially by HCPs. Also, to maximize adoption by patients and HCPs, it will be important to ensure that these technologies are accessible, cheap, and quick and easy to use.

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Partners in Research and Director of HealthiVibe, LLC. As an employee of HealthiVibe, LLC, she has worked on projects with many pharmaceutical companies, including Novartis. She also serves on the patient advisory boards of CureClick and MS SoftServe, Inc.

Compliance with Ethics Guidelines. This article does not contain any new studies with human or animal subjects performed by any of the authors.

Data Availability. Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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