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Alemtuzumab in Multiple Sclerosis: Lessons from Social Media in Enhancing Patient Care

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CME/CNE Information

Activity Available Online:

To access the article, post-test, and evaluation online, go to <http://www.cmscscholar.org>.

Target Audience:

The target audience for this activity is physicians, physician assistants, nursing professionals, and other health-care providers involved in the management of patients with multiple sclerosis (MS).

Learning Objectives:

- 1) Identify the potential challenges/inaccuracies associated with social media groups for people with MS contemplating or currently receiving alemtuzumab.
- 2) Educate patients with MS on criteria to assess social media groups focused on treatments for MS, so they better understand the purpose of these groups and how information posting is managed.

Accreditation Statement:

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the Consortium of Multiple Sclerosis Centers (CMSC), Nurse Practitioner Alternatives (NPA), and Delaware Media Group. The CMSC is accredited by the ACCME to provide continuing medical education for physicians.

The CMSC designates this journal-based CME activity for a maximum of 1.0 AMA PRA Category 1 Credit(s)TM. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurse Practitioner Alternatives (NPA) is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation.

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Laurie Scudder, DNP, NP, has served as Nurse Planner and reviewer for this activity. She has disclosed no relevant financial relationships.

Disclosures:

Francois Bethoux, MD, Editor in Chief of the *International Journal of MS Care* (IJMSC), has served as Physician Planner for this activity. He has received royalties from Springer Publishing, received intellectual property rights/patent holder from Biogen, and has performed contracted research for Biogen.

Laurie Scudder, DNP, NP, has served as Nurse Planner and reviewer for this activity. She has disclosed no relevant financial relationships.

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The anonymous peer reviewers for the IJMSC have disclosed no relevant financial relationships.

The staff at the IJMSC, CMSC, NPA, and Delaware Media Group who are in a position to influence content have disclosed no relevant financial relationships.

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Background: *Alemtuzumab is a monoclonal antibody that has been approved for the treatment of relapsing-remitting multiple sclerosis (MS). Alemtuzumab is associated with infusion reactions and potential autoimmune complications. Patient education and understanding are crucial to favorable outcomes. Our objective was to observe communication on a peer-to-peer Facebook group for content, accuracy of posts, and number of “likes” per post and to compare shared themes to current approved prescribing information and educational modules.*

Methods: *We identified a Facebook group specific to alemtuzumab in MS. A 14-day window was observed. Posts were classified as “sharing” or “seeking information.” Content analysis was used for information-seeking posts. Accuracy of replies was compared with product prescribing information.*

Results: *We reviewed 458 posts. Members contemplating receiving or currently receiving alemtuzumab primarily used Facebook for information gathering (54.6%), followed by seeking emotional support and sharing personal experiences (45.4%). Most shared experiences (83.6%) were positive. Themes for information were predominantly consistent with standard protocols. Complications discussed included infection (15.50%), bone pain (11.80%), immune thrombocytopenia (8.07%), and fatigue (7.46%). Accuracy of replies was consistent with product information except for immune thrombocytopenia.*

Conclusions: *Some patients with MS look to online groups for discussion, peer support, and information. Although written guidelines on the studied home page reinforce that online discussion “does not replace medical advice,” inaccurate information does occur. Health-care providers’ reviews of these online sites allow insight into the real-world experiences of patients receiving alemtuzumab, with potential for modification of educational approaches by health-care professionals. Int J MS Care. 2017;19:323–328.*

The continued evolution of health-care delivery to ensure the best outcomes for patients is the cornerstone of modern clinical practice. At the center of this is establishing a health-care co-partnership with patients and addressing patient concerns. The rapidly expanding online virtual communities give a more in-depth picture of patient concerns than traditional health-care professional (HCP)–patient communication. These virtual communities allow the sharing of private health information such as diagnosis, prescribed treatment, therapies, adverse events, and basic concerns. Benefits of these communities, such as emotional well-being, empowerment, and patient engagement in their health, are increasingly supported by evidence.^{1–8} Online social networks such as Facebook provide a platform for these virtual communities via interested parties setting up groups that allow interaction and support.

Alemtuzumab is a humanized monoclonal antibody against CD52 used in the treatment of relapsing-remitting multiple sclerosis (MS).⁹ Administration of this therapy

can be logistically, physically, and emotionally intense, with further rigorous long-term follow-up still required. Education of HCPs is crucial for patients to understand the process involved and potential adverse effects. Pre-screening for infectious disease, determining washout periods from other therapies, logistical advice for infusion times, premedication during infusion to reduce common infusion reactions, potential long-term autoimmune complications, and surveillance requirements are all addressed via face-to-face education and pharmaceutical information literature supplied, such as wallet alert cards and links to blood alert programs.^{10,11} This intense education process may result in early overloading with information, with patients focusing on the immediate steps of administration and defined potential risks and, only after the clinic appointment, discovering further concerns or questions that they might feel embarrassed to ask their HCP. We also recently found that the utility of mandated tools in the initiation of other MS therapy is lacking and does not always result in the degree of comprehension of possible fatal complications that is desired in patients by HCPs.¹²

Support bodies also increasingly promote this growing trend of online use. MS Australia encourages online education as a means to connect and support patients with MS, allowing the giving and receiving of practical and emotional assistance. The body has also embraced

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social media groups as a means of support to patients located at a distance, with mobility issues, or who do not want face-to-face education or interaction.¹³

To our knowledge, no studies have evaluated the accuracy of information shared on a Facebook group or its benefits as a complimentary educational tool to the HCP regarding alemtuzumab. Our aim was to determine whether a brief period of observation on a Facebook peer-to-peer group specific to alemtuzumab—Lemtrada for MS treatment Facebook group—could help us better understand patients' concerns regarding this therapy. Observation would ultimately result in more targeted education to incorporate unknown concerns and reinforce accurate information where we have observed this to be lacking.

Methods

This content analysis study evaluated posts on a closed peer-to-peer administrated Facebook group wall specific to alemtuzumab in MS. Types of posts and accuracy of shared information over 14 consecutive days were collected manually each day by one HCP (L.R.) with more than 15 years' experience in MS nursing, including participating in the CAMMS323 and CAMMS324 pivotal trials and coordinating the care and education of patients with MS receiving alemtuzumab at a major tertiary-care hospital. Data were discussed with three HCPs (one nurse, one MS specialist neurologist, and one advanced neurology trainee [L.R., N.V., and O.S.]), all with extensive MS experience. Results were compared with standard educational themes and an approved prescribing information leaflet. Fourteen days was seen as a snapshot of overall online communication.

Posts were first classified as sharing or seeking information. Information-seeking posts were coded for themes or core categories. Accuracy of replies as per product prescribing information guidelines and current alerts was scored as correct or incorrect.

Before observation, the research group posted a statement on the group's wall. This post outlined the purpose of observation and our health-care roles. Overwhelming support was received from the group. Local hospital ethics committee approval was also obtained. A low-risk approval was granted. A waiver of consent was not requested because privacy settings allow members to block the HCP if they did not want to share their posts.

Results

Guidelines by the group's administrators restrict posts that are not seen as appropriate to the intention of the

group: "This group was created to help people connect with others who have received Lemtrada and hear real experiences. We are not doctors. ALWAYS check with your doctor before trying or changing anything to do with your healthcare." A declaration of observation by HCPs on the wall of the group resulted in overwhelming support (92 "likes" and 12 positive comments). Members could change their privacy settings if they did not want the HCP to view their posts.

Over 14 consecutive days, 458 posts were reviewed. Members primarily used the Facebook group for information gathering (54.6%), followed by sharing personal experiences (45.4%). The latter resulted in more support in the form of likes (34 vs. 6.5 likes per post). Most shared experiences (83.6%) were positive. A "selfie" photograph counting down the days of infusions usually accompanied positive posts.

Complications of the medication dominated information seeking, with information on infection (15.50%), bone pain (11.80%), immune thrombocytopenia (ITP) (8.07%), fatigue (7.46%), and hydration (6.83%) featuring prominently. Table 1 compares the medical prescribing data of incidence of adverse effects derived from the pivotal trials of alemtuzumab with the dominant themes that members were posting.

Accuracy of replies to posts was predominantly consistent with local protocol and prescribing information except for ITP. Up to one-quarter of replies to this potential serious complication were inaccurate at the time of conversation. Inaccurate ITP posts (Table 2) were related to inaccurate onset time frames and description of bruising.

Discussion

To our knowledge, this is the only study published on alemtuzumab and social media. Previous studies relating to MS and social media are limited, except for chronic cerebrospinal venous insufficiency (CCSVI). Studies of CCSVI reinforced the need for HCPs to provide patients with adequate and accurate information.¹⁵ Reviewing concerns on social media by HCPs can assist in providing ongoing adequate information/education for current and future patients; the objective of this study falls in this domain.¹⁶

Administration of this peer-to-peer Facebook group by five core members who have personal experience with alemtuzumab treatment for MS seems appropriate, with clear guidelines/structure on the purpose of the group and type of information allowed. The guidelines are clearly listed on the home page of the group. Guidelines

Table 1. Prescribing information compared¹⁴ with group member themes and questions

| Category | Prescribing information | Patient concerns |
|---|---|---|
| Infusion adverse reactions | Alemtuzumab 12 mg incidence >90% Headache, rash, pyrexia, nausea, urticaria, pruritus, insomnia, chills, flushing, fatigue, dyspnea, dysgeusia, chest discomfort, generalized rash, tachycardia, bradycardia, dyspepsia, dizziness, and pain | What medication to take and why reaction is occurring; Premedication comparison between hospitals; Seeking information on organizational tips and when they will feel better; Preparation before infusion and tips with meal preparation and house maintenance; Rash cream advice |
| Infection | Alemtuzumab incidence 71% Nasopharyngitis, urinary tract infection, upper respiratory tract infection, sinusitis, oral herpes, influenza, and bronchitis Serious 2.7% Appendicitis, gastroenteritis, pneumonia, herpes zoster, and tooth infection | Hand hygiene: Promotion of continual use of hand sanitizers Animal hygiene: Can I empty kitty litter and should I board the animals until 3–4 mo after infusion? Listeria diet information: How long to be on the diet; When to start the diet; Questions on what foods to avoid and what heat level kills listeria Food hygiene: Should I wash all vegetables in vinegar? Out in the community: When should I return to work? Can I use public transport? Can I go to a football game or concert? When is air travel permitted? Dental care: Can I go to the dentist for cleaning? |
| Pain | Alemtuzumab incidence 12.3% Back pain, pain in extremity, arthralgia | Discussion on long bone pain; Why do my legs ache? Hip pain? Practical advice about what to take for this bone pain |
| Fatigue | Adverse events in study 1 and study 2 reported for alemtuzumab 12 mg–treated patients (occurring in $\geq 5\%$ of patients) Alemtuzumab (n = 811) compared with interferon beta-1a 44 μg (n = 389) 12.6% | When it occurs; Planning for the onset; Why it occurs |
| ITP | Alemtuzumab incidence 18.4% ITP occurred in 2% of Lemtrada-treated patients in clinical studies in MS and after 4 y of follow-up | Discussion of potential onset time frames; Size and shape of ITP bruises; Nose bleed relationship to ITP |
| Thyroid | Alemtuzumab incidence 2% Autoimmune thyroid disorders occurred in 36% of Lemtrada-treated patients in clinical studies and after 4 y of follow-up Serious <1% | Minimal discussion |
| Nephropathies, including anti-GBM disease | Alemtuzumab incidence 36% Glomerular nephropathies occurred in 0.3% of Lemtrada-treated patients in MS clinical trials | Urinary tract infections |
| Hydration | Alemtuzumab incidence 0.3% Elevation in serum creatinine, hematuria, or proteinuria | Needing to drink 2–3 L/d; Suggestion that oral fluids can minimize infusion adverse reactions; What types of fluids to consume? Oral vs. enteral for hydration |

Abbreviations: GBM, glomerular basement membrane; ITP, immune thrombocytopenia; MS, multiple sclerosis.

include no sales or fundraising, no discussions of alternative therapy treatments, and no discussions of religion or politics. The purpose of the group is clear: peer-to-peer support. Box 1 gives possible advice in assessing Facebook groups for information gathering. A key strength of this group lies in its core members moderating any posts not suitable for the group's intention. Core members are able to block members who do not adhere to the guidelines listed previously. This contrasts with other

observational studies where this has been of concern.¹⁷ The lack of pharmaceutical and interest group bias and outside influence on this group is viewed as valuable and positive. The group's emphasis on advice and experiences not replacing an HCP consultation is important.

Interestingly, the post about HCP observation did not change the direction of communication from peer-to-peer to peer-to-HCP. This suggests that members were not driven to ask HCPs questions or for advice

Table 2. ITP sampling of inaccurate posts and positive posts to seek medical advice

| Inaccurate posts | Accurate posts |
|---|--|
| No reason to panic, it's still too early for it to be ITP | Run this by your neurologist |
| Try not to panic; this would typically be too early for ITP | Seek urgent advice; call your doctor ASAP |
| The bruises are not a concern unless you have heaps of them that are not going away or getting bigger | Best to discuss with your physician |
| ITP takes longer to become an issue, usually quite a few months | Do not take advice over Internet; call your doctor |

Abbreviations: ASAP, as soon as possible; ITP, immune thrombocytopenia.

but were seeking peer-to-peer support in the forum, thus preserving the original purpose and integrity of the group.

The finding of 54.6% of patients seeking additional information outside the medical consultation is supported by other studies in MS.^{18,19} Information sought, including that on fatigue, infection, bone pain, and hydration in the acute to subacute stage of treatment initiation, highlights an aspect of care and education that can be improved on when communicating the treatment process. The group provides practical tips on coping through the early stages of the infusion, with an emphasis on “what the patient should do.” As the group grew, it developed a collective wisdom, which was reflected in its notes or “pinned” section on commonly asked questions. Evidence suggests that this can eventually become a valid supplement of patient education.¹⁹

Other researchers have questioned the source of information posted on medical Facebook groups for its lack of scientific rigor; however, advice or strategies in coping do not necessarily need such rigor.²⁰ Table 1 illustrates the contrast in information on this platform from the prescribing information, highlighting again

the practical information-sharing element of online peer groups. Table 1 is an attempt to illustrate the dichotomy between patient concerns and medical risks. Percentages used for risk were from combined pivotal trial data highlighted in the prescribing information. This contrast in information shared also informs the HCP of strategies in preinfusion education consultations and acceptance that patients turn to alternative groups for different information. Peer support is more favored for practical solutions and coping strategies.²¹

The inaccurate advice given on ITP highlights one of the possible dangerous flaws of online platforms. Among the inaccuracies given was the concept of a clear time of onset of ITP, which growing evidence dispels, and an untrue impression of what constitutes ITP symptoms.²²⁻²⁴ Group members advising that the other member seek medical advice balances these inaccuracies. It may also be that the 14-day observation window was not long enough for the group to self-auto correct, as has been suggested in other studies.^{16,25} Autoimmune thyroid disease and nephropathies were minimally discussed, reinforcing the observation of immediate practical issues being paramount for members.

Approximately 45% of posts focused on sharing experiences and emotions. An announcement about one's own immediate experience and self-disclosure online, some authors have suggested, comes with an expectation for reciprocation such as “liking.” Sharing stories is a valid tool to make sense of an experience and, as some authors suggest, may allow a reduction in anxiety.^{14,26} Sharing posts resulted in a fivefold increase in likes, highlighting the possible desire of group members to support one another and reciprocate when there was a

Box 1. Checklist to assess medical Facebook groups

- Are there clear guidelines to the intention of the group?
- Are there moderators/administrators with whom communication can be private to report concerns?
- Are there rules as to consequences of not keeping to the intent of the group?
- Are there document pages with updated prescribing information from regulatory bodies?
- Are “pinned” documents referenced?

PracticePoints

- The social media platform Facebook is used by people contemplating receiving or currently receiving alemtuzumab for MS primarily for peer information.
- Inaccurate safety information can occur on peer-to-peer Facebook groups, suggesting the value of health-care professionals engaging with these platforms.
- Social media platforms such as Facebook allow insight into real-world concerns of patients receiving or contemplating receiving alemtuzumab and enhance future directions for education and support by health-care professionals.

self-disclosure. Positive experience posts were frequent (83.6%) and were often accompanied by encouraging pictorial themes, such as a selfie each day of the infusion, or positive analogies, such as achieving lifetime events as a countdown in kilometers for a marathon, while reinforcing the merits of treatment and the reality that not all patients develop adverse effects. Postinfusion photographs with captions of “look what I can do now” were common.

Although negative sharing was minimal among members, it certainly does highlight a realistic aspect to group members that is essential in forming a balanced view before embarking on treatment. Patients share their disappointment in lack of improvement or perceived deterioration. The remainder of themes were logistical, with minor frustrations expressed regarding bookings, insurance, and logistics.

We acknowledge a variety of limitations, including a brief period of observation, manual review, sampling from only one group, and an inability to confirm members' true demographic data.

Conclusion

These findings illustrate the potential use of the social media platform Facebook in shaping patients' knowledge and driving the concept of the informed patient. Social media platforms, such as the sampled Facebook group, highlight patients' concerns and misconceptions while clearly demonstrating strengths of this information-sharing approach. Continual observation of these groups will help HCPs better understand patients' needs and match patients' concerns with improved services and education in a variety of formats. □

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