

Patients understanding of the potential side effects, effectiveness and required safety monitoring of their current disease modifying therapy

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Introduction:

York Teaching Hospital Trust provides care for patients in York, Scarborough, Bridlington, Malton, Selby and Easingwold communities. York Hospital is a Multiple Sclerosis (MS) treatment prescribing centre with over 300 patients been prescribed disease modifying therapies. The available treatment options for patients with relapsing remitting MS has increased exponentially over the years. The treatments are more complex with some potentially serious side effects. Similarly the sources of information available to patients has increased dramatically.

Aim

An audit was designed to gain an insight into patients understanding of the potential side effects, effectiveness, risks and safety monitoring involved with their treatment. Two disease modifying treatments were chosen and compared, Alemtuzumab and Dimethyl Fumarate

Method

Included in the audit were eight patients who had been administered Alemtuzumab and eight patients who had commenced on Dimethyl Fumarate during the last three years. The data was collected through a scripted phone call. A random filter was used from the treatment spread excel sheet to filter out the eight patients for each treatment.

Questionnaire used in audit

- On a scale of 1 (not happy)-10 (very happy) how happy are you with your understanding of the potential side effects or complications of Dimethyl Fumarate and Alemtuzumab?
- Who would you ask or what sources would you use if you wanted to get more information about your disease modifying treatment?
- Can you recall what the potential side effects of Dimethyl Fumarate/Alemtuzumab were at
 - At the time of choosing this treatment
 - The long term side effects/risks
- What safety monitoring do you require when on this treatment?
- What potential complications are we monitoring for?
- How effective do you feel Dimethyl Fumarate/Alemtuzumab is on a scale of 1 (no benefit)-10 (most effective)
- How risky do you feel Dimethyl Fumarate/Alemtuzumab is on a scale of 1 (completely safe)- 10 (most risky)
- How happy are you with your understanding of the potential side effects/complications of Dimethyl Fumarate/Alemtuzumab on a scale of 1 (not happy) – 10 (extremely happy)

Results:

Patient satisfaction of their treatment was quite consistent. Most patients felt that they had a good understanding of their Disease Modifying Therapy.

The most popular sources of information for patients was MS nurses, second was forums with the Neurologist and GP's been the least popular sources of information.

When patients were asked about the potential side effects at the time of choosing their treatment, the results demonstrated that patients had a good understanding of the initial effects of gastric upset and facial flushing with Dimethyl Fumarate and infusion associated reactions, rash and changes in blood pressure and pulse with Alemtuzumab.

"I would rather to speak to my HCP then use the internet. I think the chat rooms can be scary and would make me feel the treatment is more risky"

"I never think about the risks as I feel so well"

Regarding long term side effects, all patients who had received Alemtuzumab identified thyroid disease but less than 30% mentioned Immune thrombocytopenic purpura (ITP) and kidney disease.

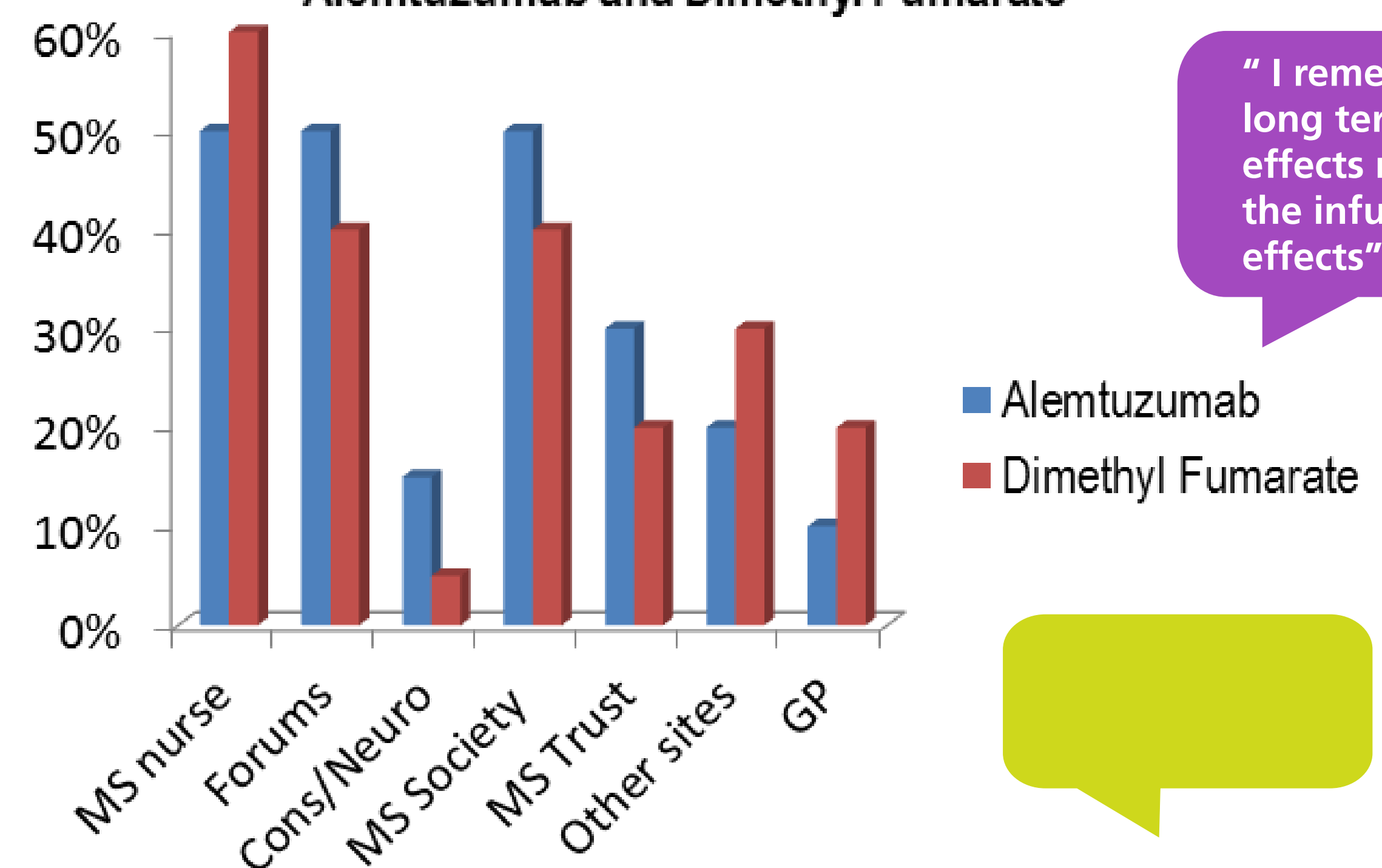
"I find the forums really helpful to chat to people who are going through the same treatment"

For patients receiving Dimethyl Fumarate 50% mentioned Progressive multifocal leukoencephalopathy (PML) and 20% were unsure what were the long term side effects.

Regarding effectiveness there were three patients who had received Alemtuzumab and one patient who was on Dimethyl Fumarate who felt that they would need a year before knowing whether their treatment was effective.

"The benefits to me outweigh the risks"

Sources of information patients used to gain more information about Alemtuzumab and Dimethyl Fumarate



"I remember the long term side effects more then the infusion side effects"

Conclusion:

Overall patients felt satisfied with their level of understanding. Although there were some inconsistencies shown in their understanding of the long term side effects.

The most popular sources of information were internet based and forums. This could be due to easy accessibility. 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 when making treatment decisions (Kantor,2018)

It appears that other peoples opinions and personal experiences may seem to have an influence more than previously thought. It maybe

even more influential than a healthcare professionals opinion. The perception of risk seemed quite variable with none thinking that the complications of Alemtuzumab were life threatening. We know that despite regular monitoring some patients are unwilling to take the risk of developing serious side effects (MS Trust,2018), however what was demonstrated from the audit was that most patients said the benefits outweighed the risks when making the decisions about their therapy. The perception of risk to patients is individual. As Healthcare Professionals we need to continue monitoring patients ongoing understanding of the risks and side effects of treatments throughout the patients journey on therapy.

Recommendations

- Following this audit the recommendations are that as healthcare professionals we continue to ensure that patients are receiving accurate information about their disease modifying treatment as patients are increasingly using the internet and forums as sources of information.
- When reviewing patients to check their ongoing understanding of their treatment, side effects and the monitoring required.
- Following the audit a new consent form has been devised to be used for each patient commencing on any of the disease modifying therapies. As perception of risk is individual, a consent for each of the treatments will enable healthcare professionals to check patients perception and understanding of their treatment at the time of consenting.
- To re audit again in 12 months' time