

The emotional impact of an opportunistic infection in patients treated with highly effective therapies: The supportive role of the Multiple Sclerosis Team

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Conclusion:

Our case studies illustrate the emotional distress that a diagnosis of a rare opportunistic infection in patients treated with highly efficacious treatments can trigger. Patients can experience grief, loss and anxiety. Fear of removal or continuance of highly successful treatment requires counseling and support. Anger and bargaining is common. The MS team is crucial to assist not only in the diagnosis and treatment regimes of these infections but support in the emotional journey patients face.

Introduction:

Therapeutic management of multiple sclerosis (MS) has dramatically expanded in the last 10 years. Highly effective disease modifying treatments have given patients much optimism as health care providers (HCPs) have sought to treat to the concept of *no evident disease activity*¹.

Patients have been encouraged to be co-partners with their HCPs in discussing efficacy and risks of their mutually agreed MS treatments. Highly effective therapies have enabled patients to resume or maintain an optimal quality of life.

Whilst each therapeutic treatment lists rare opportunistic infections (OIs) in their prescribing/product information, we are now seeing post marketing a rise in their numbers.²

In patients where these rare OIs occur there appears a similar emotional impact to patients initially diagnose with MS, but with the added burden of possible withdrawal of a highly efficacious therapy or fear of continuation of a highly efficacious therapy.

Objectives:

To describe the emotional impact in patients and their families during and post diagnosis of an unexpected severe opportunistic infections. (OIs) in case studies.

Case Study 1:

Cryptococcal-meningoencephalitis in fingolimod treated patient

61 year old caucasian female diagnosed with Relapsing Remitting Multiple Sclerosis (RRMS) in 2006. Previously treated with natalizumab 300mg but switched to fingolimod 500mcg in 2012 due to long term safety concerns re her sero-positive John Cunningham Virus Index (JCV).

Her MS disease activity remained stable both clinically and radiologically. She was actively involved in risk/benefit discussion of her MS treatments.

In 2016 she developed cryptococcal-meningoencephalitis (CM) with secondary hydrocephalus. The patient commenced flucytosine and amphotericin for management of Cryptococcus infection. OIs with fingolimod have become increasingly recognised with post marketing surveillance. There are now 17 reported cases of CM world wide. During her admission expanded disability scoring system (EDSS) increased to 5.5 with functional score (FS) ambulation 4 and FS mental assessment 2. Multiple medical and nursing teams were involved in her inpatient and rehabilitation care. The patient had prolonged inpatient acute stay followed by inpatient rehabilitation. She was discharged home. on changed MS therapy: Glatiramer Acetate 40mg three times weekly.

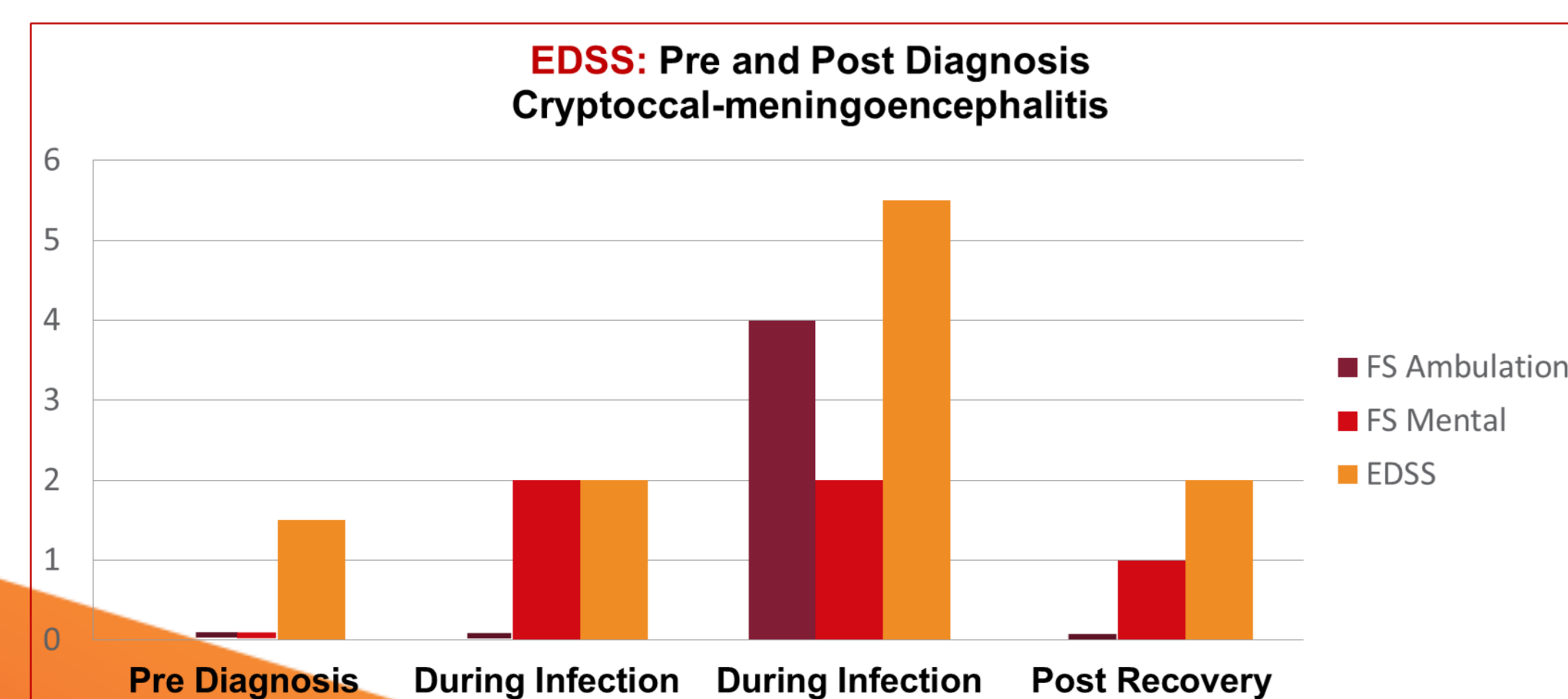


Diagram 2: Case Study 1
Multiple Medical Teams involved in care

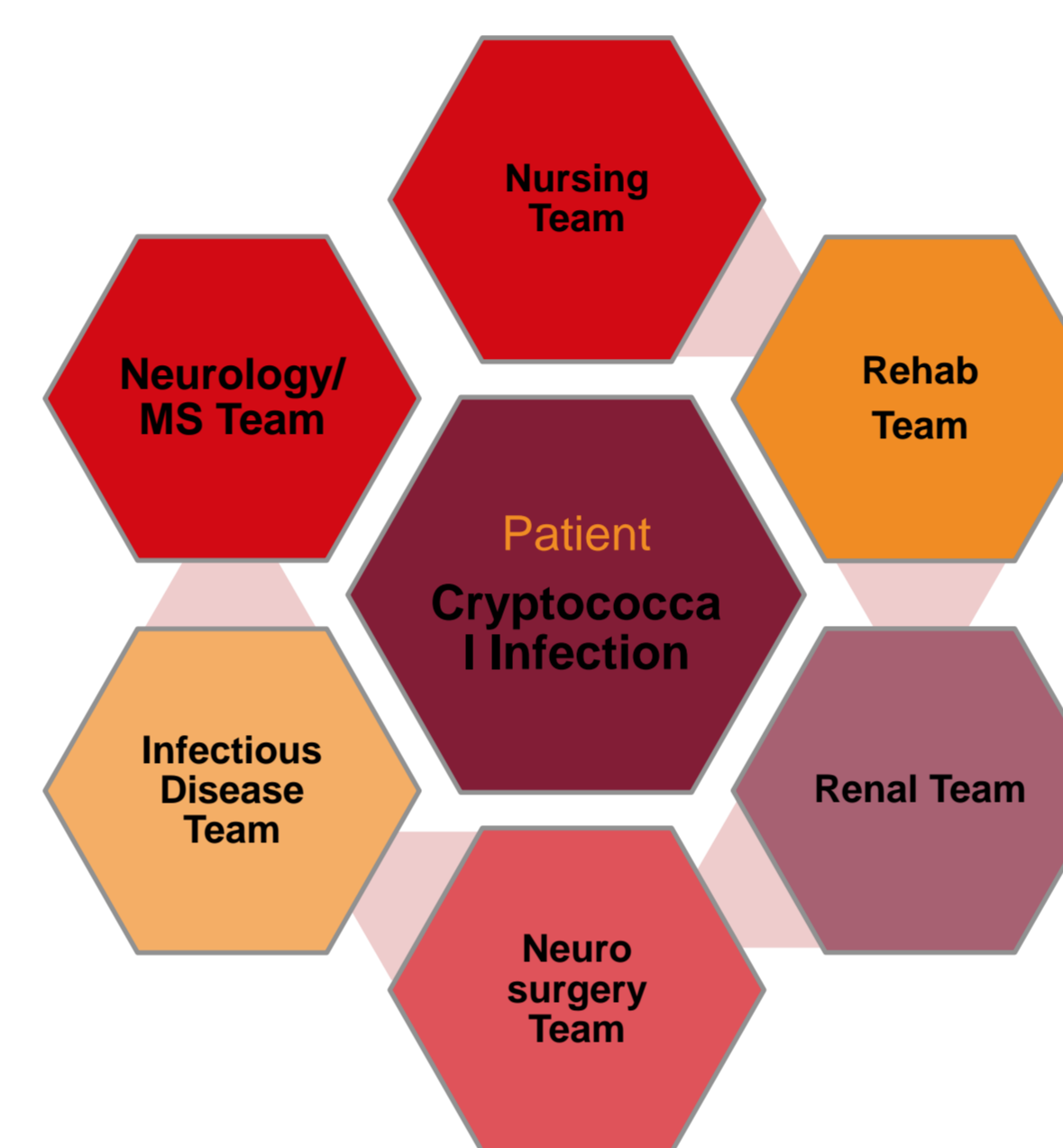
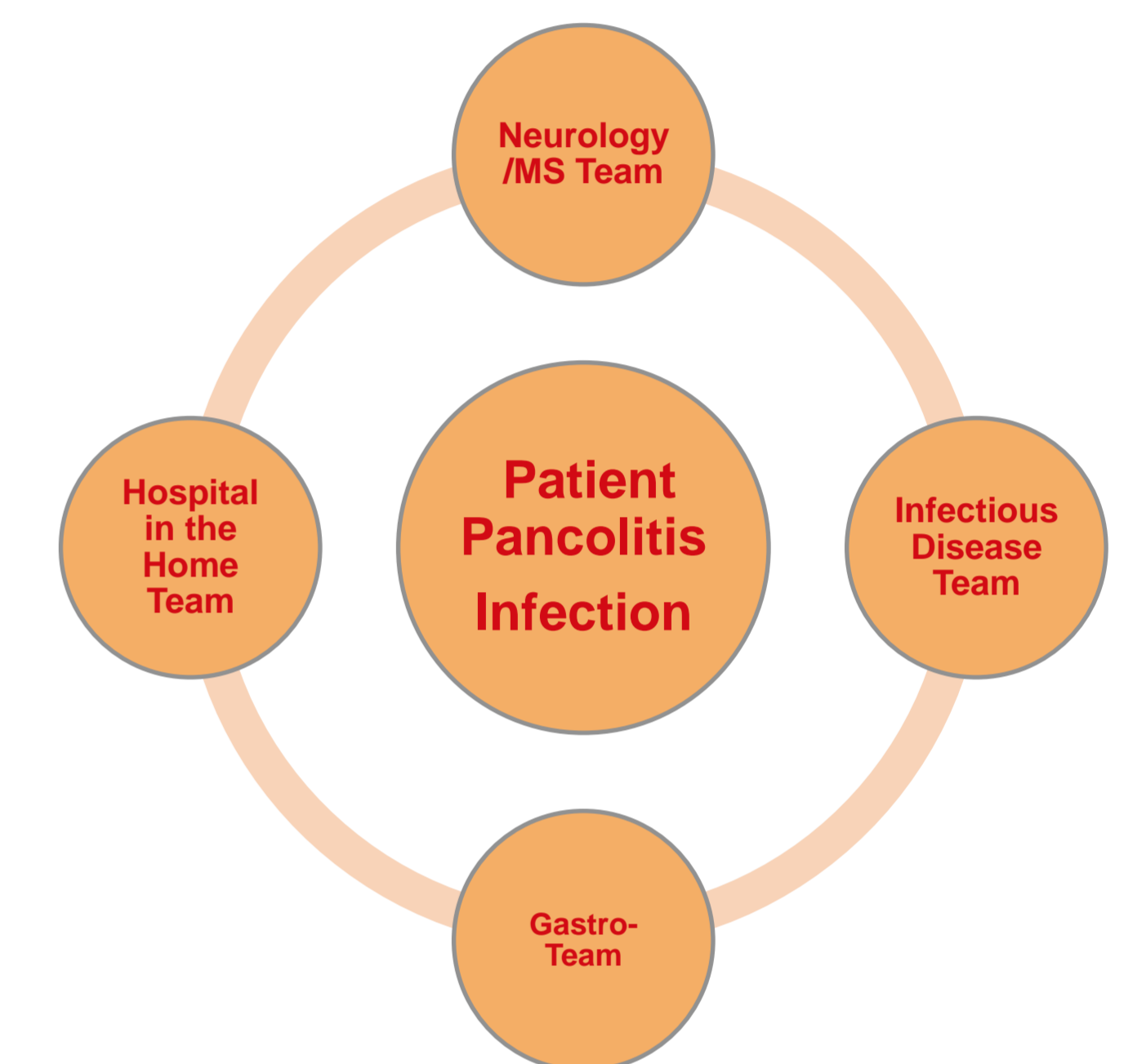


Diagram 3: Case Study 2

Multiple Medical Teams involved in care



Case Study 2:

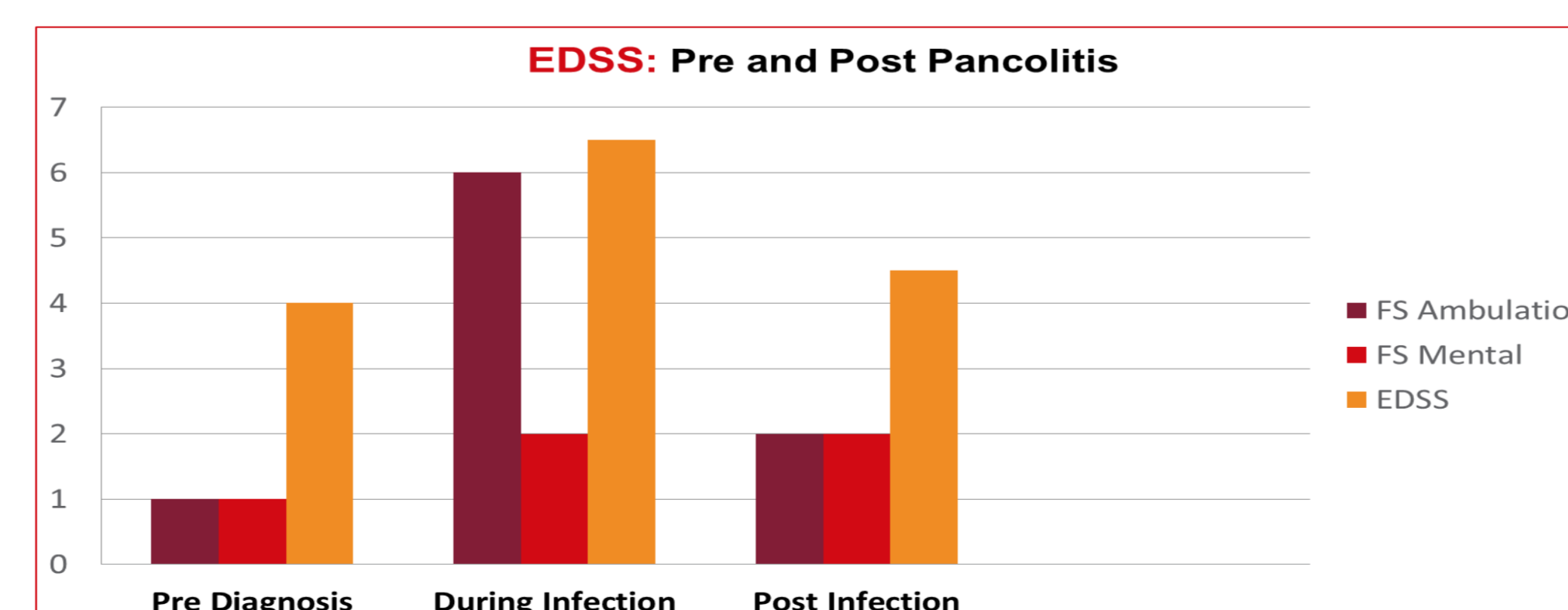
Pancytopenia in alemtuzumab treated patient³

47 year old Caucasian male diagnosed RRMS in 2007. Previously treated with natalizumab 300mg but switched to alemtuzumab in 2015 due to long term safety concerns re his sero-positive JCV Index. His MS activity on natalizumab 300mg had remained clinically and radiologically stable. He was actively involved in risk/benefits discussion of his MS treatments with his HCP's

In 2016 he presented 8 hours post day 4 of 5 of alemtuzumab first year infusion (12mg/100mls) with abdominal cramps, fever, rigors and profuse diarrhoea with subsequent rectal bleeding. Blood cultures grew extended spectrum betalactamase producing Escherichia coli (ESBLEC). Treated with hydrocortisone and tazocin and later meropenem.

During his admission EDSS increased to 6.5. Frequent "Met calls" occurred during early admission for haemodynamic instability. Multiple medical and nursing teams were involved in his care.

He recovered from pancytopenia and was discharged home. He was advised that he could continue with the next cycle of alemtuzumab in 52 weeks as planned.



Discussion:

Both these case studies illustrate the complex emotional and physical needs of current MS patients⁴. Both patients were seeking highly efficacious treatments and had discussed the risk/benefit ratios with their MS team. Although OIs are rare, the emotional distress suffered by both patients in their journey is worth reflecting upon.

Both patients expressed fear, anger and anxiety during and post OIs. Factors that impacted on their stress levels were;

- The severity of the infection; both patients felt a high level of threat
- The lack of predictability of the rare OIs. Both events were acute and the patients were unable to prepare for the stressor
- The uncertainty of recovery from the OIs
- Fear of MS progression
- Fear of change or continuance of current MS treatment

Initially, additional resources were required by the MS treating team to help the patients interpret the diagnosis and treating regimes of the OIs. These patients had developed a long standing relationship with the MS team and this constant presence reassured them when they were exposed to multiple health care providers.

Post recovery extensive family counselling was required in both cases. Follow up MS appointments were prolonged. Medical teams should be prepared to deal with similar events with prompt, extended multidisciplinary support.

Further research to quantify the specific concerns raised would be of interest.

Disclosures:

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