(S93) RELAPSING MULTIPLE SCLEROSIS PATIENTS’ EXPERIENCE WITH TYSABRI: A PHENOMENOLOGICAL INVESTIGATION

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Background: This phenomenological investigation was undertaken to gain a better understanding of multiple sclerosis (MS) patients’ experience with Tysabri treatment and its impact on their quality of life (QOL). Objectives: Information will be used to educate professionals involved in MS patient care as well as patients and families considering treatment with Tysabri. Methods: Twenty patients with MS who were receiving Tysabri treatment were recruited by the care providers at the Baird MS Center in Buffalo, NY. Patients were invited to participate if they had relapsing MS, had received at least six treatments with Tysabri, and could articulate their experience. The Atlas.ti qualitative data-analysis program was used to manage the data. Heideggerian phenomenology methods were applied. Results: Ten major themes emerged from the data analysis: QOL, processes associated with Tysabri treatment, switching, uncertainty, fear, decision points, avoidance, side effects, support, and improvement. QOL was a pervasive theme among all MS participants and is defined in relation to their ability to live a “normal” life without interruption from MS symptoms. Tysabri contributed to a good QOL by “allowing them to get back into the game of life” and liberating them from the burdens of other treatments. Fear is part of the experience for everyone. Fear of the future appears to be the motivating force for patients to consider medicines with risks such as Tysabri. The MS experience is wrought with decision points throughout the disease. Patients discuss motivations behind the decision process and influences from other people. Side effects of medicines are mentioned by all. Many try to balance the burden of coping with side effects with the benefits the drugs may offer. Support comes in many forms. Family and provider support are crucial. Many find peer support important while receiving infusions. Most participants note an “improvement” since starting Tysabri. Those who do not improve question whether the drug is working because they hear about others getting better. Conclusions: The results of this study will guide patient teaching about what to expect with Tysabri treatment. We will also be better able to educate providers on ways to facilitate the overcoming of barriers and offer more effective support and monitoring.

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