

## **Health-Related Quality of Life with Diroximel Fumarate in Patients with Relapsing Forms of Multiple Sclerosis: Findings from Qualitative Research Using Patient Interviews**

Mark Gudesblatt,<sup>1</sup> Cortnee Roman,<sup>2</sup> Barry A. Singer,<sup>3</sup> Hollie Schmidt,<sup>4</sup> Jessica Thomas,<sup>5</sup> Sai L. Shankar,<sup>6</sup> Jennifer Lyons,<sup>6</sup> Shivani Kapadia,<sup>6</sup>

<sup>1</sup>South Shore Neurologic Associates, Patchogue, NY, USA

<sup>2</sup>Rocky Mountain Multiple Sclerosis Clinic, Salt Lake City, UT, USA

<sup>3</sup>The MS Center for Innovations in Care, Missouri Baptist Medical Center, St Louis, MO, USA

<sup>4</sup>Accelerated Cure Project for Multiple Sclerosis, Waltham, MA, USA

<sup>5</sup>MS/Chronic Illness Counselor & Person Living with MS, Highpoint, NC, USA

<sup>6</sup>Biogen, Cambridge, MA, USA

**Corresponding author:** Shivani Kapadia, Biogen, 225 Binney St., Cambridge, MA, USA; email: [shivani1215@gmail.com](mailto:shivani1215@gmail.com)

**Supplementary Material**

## **Supplementary List. Patient Interview Guide**

### **List of interview questions**

#### **I. Patient Overview**

1. Let's start with telling me a little about you, such as your age, who you live with, whether or not you work.

Data collected/probing:

- a) Age
  - b) Marital status
  - c) Children
  - d) Living situation
  - e) What is your current work situation and/or environment? Or obligations?
    - Working from home because of COVID-19? Any changes in status change or schedule due to COVID-19?
2. What hobbies and activities do you enjoy?

#### **II. MS Impacts**

3. When were you first diagnosed with MS?
4. If you could choose a color to represent how you feel about your health at this time, what color would you choose? What makes you choose that color?
  - a. Are you in a good spot? Is there something that can be improved?
5. How does MS affect your daily life?
6. What affects you the most about living with MS?
7. What has been your experience living with MS during the coronavirus pandemic?

#### **IV. Treatment Selection and Perceptions**

8. Now I'd like to talk about treatments. Can you choose 3 adjectives that best represent your perceptions in general about current treatments for MS? What made you choose these words? Is there an adjective not listed here that fits better with your perception of the current treatments?

10. What are your goals with treatment?
11. If you had to choose three aspects of your life which are most important to retain through your MS treatment, what would they be?
12. What treatments have you taken for your MS?
- b) As applicable:* Why did you switch from [previous treatment]?
13. What is most important to you in selecting a treatment?
- a. Does the way you take it and how it is administered matter, including whether or not you need to take it with or without certain foods?
  - b. Do you ever consider taking, or have you taken, naturopathic treatments? What are your thoughts on these?
14. Tell me about the conversations you had with your doctor about selecting Vumerity®
- a. How would you describe your role in selecting your treatment?
  - b. Who first brought up Vumerity (your doctor/yourself)?
  - c. What were some of the reasons for starting Vumerity®?
  - d. What would you say most influenced your choice of Vumerity®?
  - e. Did you do any research on Vumerity before you started it?
  - f. Is it important to you how the treatment works in the body to bring about an effect?
    - i. Are you familiar with how Vumerity works?
  - g. Before taking Vumerity, were any risks discussed with you? What did you think of the risks?
  - h. What do you think about Biogen's patient support program?
15. Looking at the pictures on your screen which picture would you pick that best represents how you felt about your QOL prior to taking Vumerity®? What made you choose that picture?
- a. Now looking at the pictures again choose a picture that represents how you feel about your QOL now on Vumerity®? What made you choose that picture?

## **V. Treatment Impacts**

16. What was/has been your experience on Vumerity®?
- a. What are things you like about Vumerity? Don't like?
  - b. How has it impacted your daily life?

- c. How has treatment affected you emotionally?
  - d. Have aspects of your life improved since taking Vumerity®? Worsened?
17. How has your work-life changed since starting Vumerity®?
- a. (if not working) How has meeting daily obligations changed since starting Vumerity®?
18. Thinking back to the treatment(s) you had taken prior to Vumerity® and now, can you describe how your current experience compares to your past experience with treatment?
19. How difficult or easy is it to take Vumerity® as prescribed on a 1 to 7 scale where 1 is very difficult and 7 is very easy?
- a. How did you come up with [X]?
  - b. Can you describe how you take Vumerity®, including when and how often?
  - c. Do you take it with certain foods?
  - d. Have you changed your diet since you started taking Vumerity®?
  - e. Have you changed the timing of your meals?
  - f. What may help you to stick to the treatment regimen?
  - g. How does this differ, or not, from your prior treatments? Is your ability to stick to your treatment regimen better with Vumerity®?
20. Do you take other medications as well as Vumerity? What are these for?
- a. Did you take medications with your other MS treatments?

**Side Effects**

21. Have you had side effects on Vumerity®?
- a. If yes, can you describe them?
  - b. Have you had [side effect] in the past? With other MS treatments? Can you describe them?
  - c. Were you taking the treatment with certain foods when the [side effect] occurred?
22. How did [side effect] affect your daily life/lifestyle?
- a. On a 1 to 7 scale where 1 is not at all severe and 7 is very severe, how would you rate their severity?
  - b. Did they impact your work? How? (as applicable)

- c. When did they occur? Can you describe the frequency and how long they lasted (e.g., hours/days)?
- d. Did you do anything to try to relieve them? Did you take medication for them?

***Other Impacts***

- 23. What are the main reasons for your ability to stay on your current treatment/Vumerity®?
- 24. Is there additional information you wish you had been told before starting your treatment journey?

**VI. Wrap-up (1 min)**

- A. Anything else about the impacts of treatment on your life that you would like to add?
- B. Thank you so much for your time and feedback.

**Supplementary Figure S1. Adjective List**

Necessary	Fatiguing	Exciting
Discouraged	Painful	Concerning
Effective	Optimistic	Innovative
Empowering	Comfortable	Impressive
Superior	Hopeful	Comforting
Dependable	Supportive	Frustrated
Uplifted	Sad	Encouraged
Strong	Weak	

**Supplementary Table S1** Saturation grid of per patient responses on impacts of DRF on life

	P001	P002	P003	P004	P005	P006	P007	P008	P009	P010	P011	P012	P013	P014	P015	P016	P017	Total
<b>Daily Life</b>																		
No impact		X	X	X	X	X		X	X			X		X	X		X	10/17 (59%)
Improvement in symptoms	X										X							2/17 (12%)
Fewer side effects										X	X		X				X	4/17 (24%)
Helped patient regain QoL											X							1/17 (6%)
More tied to a treatment regimen			X				X			X								3/17 (18%)
Less effective than previous medication							X									X		2/17 (12%)
<b>Work Life / Obligations</b>																		
No impact			X	X	X	X		X	X	X	X	X	X	X	X		X	13/17 (76%)
<b>Emotional Impact</b>																		
No impact				X			X	X					X		X			5/17 (29%)
Less anxiety about administering medication		X	X			X								X				4/17 (24%)
Less stress about paying for medication														X				1/17 (6%)
Has given patient life back											X							1/17 (6%)
Increased anxiety due to uncertainty of DRF's effectiveness										X							X	2/17 (12%)

Feel like a guinea pig										X								1/17 (6%)
Anxiety about missing doses					X													1/17 (6%)
Frequent administration is constant reminder of disease state									X									1/17 (6%)
Perceived lack of effectiveness led to anxiety																X		1/17 (6%)
<b>Impact on Diet and Eating Schedule</b>																		
No impact on diet	X	X	X	X			X	X	X	X		X	X	X	X		X	13/17 (76%)
No impact on timing of meals	X		X	X	X	X	X	X	X		X		X		X		X	12/17 (71%)
More aware of food restrictions (e.g., limiting fat intake, no alcohol)			X					X	X	X							X	5/17 (29%)
Diet limited significantly to avoid GI side effects											X							1/17 (6%)

DRF diroximel fumarate, GI gastrointestinal, QOL quality of life

P001–P017, patient designations



**Supplementary Table S2** Saturation grid of per patient responses on positive and negative features of DRF

<b>Positive Features</b>	P001	P002	P003	P004	P005	P006	P007	P008	P009	P010	P011	P012	P013	P014	P015	P016	P017	<b>Total</b>
Mode of administration		X	X	X	X	X	X	X		X		X	X	X	X	X	X	14/17 (82%)
Easier or more convenient than injectables or infusions		X	X	X				X	X			X	X	X	X		X	10/17 (53%)
Fewer MOA-related side effects		X		X														2/17 (12%)
Positive experience with Biogen			X	X	X	X		X						X			X	7/17 (41%)
Effectiveness	X	X	X	X				X			X	X	X	X	X		X	11/17 (65%)

<b>Negative Features</b>	P001	P002	P003	P004	P005	P006	P007	P008	P009	P010	P011	P012	P013	P014	P015	P016	P017	<b>Total</b>
Intense treatment regimen (frequent dosing schedule / many pills per dose)	X		X		X		X	X		X	X					X	X	9/17 (53%)
Food requirements	X		X	X	X		X				X			X				7/17 (41%)
Mode of administration	X						X		X									3/17 (18%)
More difficult than injectables, infusions	X								X									2/17 (12%)
Pills perceived to be less effective	X																	1/17 (6%)
Bothersome or debilitating side effects							X				X							2/17 (12%)
Perceived lack of effectiveness							X									X		2/17 (12%)

DRF diroximel fumarate, MOA mechanism of action

P001–P017, patient designations