ONLINE ONLY

Supplemental material

Development and validation of a patient-centered, meningioma-specific quality-of-life questionnaire
Baba et al.
https://thejns.org/doi/abs/10.3171/2020.11.JNS201761

DISCLAIMER The Journal of Neurosurgery acknowledges that the following section is published verbatim as submitted by the authors and did not go through either the Journal’s peer-review or editing process.
Please fill in this survey to tell us about your experience in the last 7 days.

Circle 1 number for each line which best reflects your experience.

### During the past 7 days, did you have:

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>1</th>
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<tbody>
<tr>
<td>1. Problems with your eyesight</td>
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<td>2. Trouble telling people what you want</td>
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<td>3. Trouble telling people how you feel</td>
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<td>4. Trouble finding the right words</td>
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<td>5. Trouble remembering things</td>
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<td>6. Weak hand, arm, leg, foot, or face</td>
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<td>7. Numb hand, arm, leg, foot, or face</td>
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<td>8. Headaches</td>
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<td>10. Lower level of energy</td>
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<td>11. Seizures</td>
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<td>12. Problems with your hearing</td>
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<td>13. Problems with swallowing</td>
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<td>14. Slurred speech</td>
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<td>15. Noticeable improvement in your symptoms</td>
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</table>

### During the past 7 days, did you:

<table>
<thead>
<tr>
<th>Question</th>
<th>Definitely false</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>4</th>
<th>Definitely true</th>
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<tbody>
<tr>
<td>16. Want to do more, but your body was not able to</td>
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<td>17. Need naps during the day</td>
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<td>18. Take part in physical activity without the fear of getting worse</td>
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Meningioma Quality of Life Questionnaire (MQoL)
<table>
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<tr>
<th>Question</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Sometimes</th>
<th>Often</th>
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<tbody>
<tr>
<td>During the past 7 days, <strong>did you:</strong></td>
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<tr>
<td>19. Feel mentally tired</td>
<td>Never</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>20. Pay attention to others</td>
<td>Never</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>21. Think clearly</td>
<td>Never</td>
<td>0</td>
<td>1</td>
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<td>3</td>
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<tr>
<td>22. Feel confused</td>
<td>Never</td>
<td>0</td>
<td>1</td>
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<td>3</td>
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<tr>
<td>23. Feel frustrated with how long it’s taking to feel better</td>
<td>Never</td>
<td>0</td>
<td>1</td>
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<td>3</td>
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<tr>
<td>24. Feel frustrated that you can’t do things that you could do before</td>
<td>Never</td>
<td>0</td>
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<tr>
<td>During the past 7 days, <strong>did you:</strong></td>
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<tr>
<td>25. Feel that you have support from your family</td>
<td>Never</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26. Need help from your family to do tasks like cleaning, doing groceries, preparing food, managing finances</td>
<td>Never</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>27. Need help from family members more than usual</td>
<td>Never</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>28. Talk about your meningioma with your family</td>
<td>Never</td>
<td>0</td>
<td>1</td>
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<tr>
<td>29. Argue with family about your care</td>
<td>Never</td>
<td>0</td>
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<td>30. Notice a change in your responsibilities within the family</td>
<td>Definitely false</td>
<td>0</td>
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<tr>
<td>31. Feel close to your family</td>
<td>Definitely false</td>
<td>0</td>
<td>1</td>
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<tr>
<td>32. Feel close to your friends</td>
<td>Definitely false</td>
<td>0</td>
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<tr>
<td>During the past 7 days, <strong>did you:</strong></td>
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<tr>
<td>33. Feel mentally tired when out with friends or in public</td>
<td>Never</td>
<td>0</td>
<td>1</td>
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<td>34. Feel more sad than usual</td>
<td>Definitely false</td>
<td>0</td>
<td>1</td>
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<tr>
<td>35. Feel lonely</td>
<td>Definitely false</td>
<td>0</td>
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<tr>
<td>Question</td>
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<tr>
<td>During the past 7 days, did you:</td>
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<tr>
<td>36. Feel isolated</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>37. Feel helpless</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>38. Feel easily annoyed</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>39. Feel easily angered</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>40. Feel scared</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>41. Feel hopeless</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>42. Feel that things will get better</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>43. Feel that you are the same person as you were before the meningioma</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>44. Worry that the meningioma will grow back</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>45. Feel anxious around getting your MRI results</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>46. Feel unsure if your symptoms will go away</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>47. Worry about having to depend on others to do daily activities in the future</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<td>48. Want to go back to work, even if you can’t</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>49. Feel unsure about the extent of your recovery</td>
<td>Definitely false 0 1 2 3 4 Definitely true</td>
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<tr>
<td>50. Worry about how your condition will affect your family and friends</td>
<td>Never worried 0 1 2 3 4 Always worried</td>
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<tr>
<td>51. Worry about how you will manage your home</td>
<td>Never worried 0 1 2 3 4 Always worried</td>
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<tr>
<td>52. Worry about how you will manage your finances</td>
<td>Never worried 0 1 2 3 4 Always worried</td>
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<tr>
<td>53. Worry that you will not be able to move parts of your body in the future</td>
<td>Never worried 0 1 2 3 4 Always worried</td>
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<tr>
<td>54. Have concerns that you will lose your ability to understand what is happening in the world around you</td>
<td>Not concerned 0 1 2 3 4 Always concerned</td>
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## MQoL – Meningioma Quality of Life Questionnaire
Version 1, August 14, 2019

<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
<th>Answer Options</th>
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<tbody>
<tr>
<td><strong>During the past 7 days, did you:</strong></td>
<td></td>
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<tr>
<td>55. Worry that you will die</td>
<td>Never worried, 1, 2, 3, 4</td>
<td>Always worried</td>
</tr>
<tr>
<td>56. Feel confidence in your doctors</td>
<td>No confidence, 1, 2, 3, 4</td>
<td>Very confident</td>
</tr>
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<td><strong>During the past 7 days, did you:</strong></td>
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<tr>
<td>57. Feel good about yourself</td>
<td>Never, 1, 2, 3, 4</td>
<td>Always</td>
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<tr>
<td>58. Have to adjust to changes in your life</td>
<td>Never, 1, 2, 3, 4</td>
<td>Always</td>
</tr>
<tr>
<td>59. Feel that you look like yourself</td>
<td>Definitely false, 1, 2, 3, 4</td>
<td>Definitely true</td>
</tr>
<tr>
<td>60. Worry about how your hair will grow back</td>
<td>Never worried, 1, 2, 3, 4</td>
<td>Always worried</td>
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<tr>
<td>61. Worry about how people will look at you</td>
<td>Never worried, 1, 2, 3, 4</td>
<td>Always worried</td>
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<td><strong>During the past 7 days, could you:</strong></td>
<td>N/A = Not Applicable</td>
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<tr>
<td>62. Go grocery shopping</td>
<td>Yes, No, N/A</td>
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<td>63. Do heavy housework like vacuuming, mowing the lawn, shovelling snow</td>
<td>Yes, No, N/A</td>
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<td>64. Prepare food for yourself</td>
<td>Yes, No, N/A</td>
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<tr>
<td>65. Go back to work (including work at home)</td>
<td>Yes, No, N/A</td>
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<td>66. Walk UP the stairs</td>
<td>Yes, No, N/A</td>
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<tr>
<td>67. Walk DOWN the stairs</td>
<td>Yes, No, N/A</td>
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<td>68. Drive</td>
<td>Yes, No, N/A</td>
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<tr>
<td><strong>During the past 7 days, did you:</strong></td>
<td>N/A = Not Applicable</td>
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<td>69. Know what is safe for you to do (e.g. daily activities, physical activities)</td>
<td>Yes, No, N/A</td>
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<td>70. Know where to look for good information about your diagnosis</td>
<td>Yes, No, N/A</td>
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Supplemental Data

Supplemental File 1: Interview Guides

Interview Guide for Patients / Caregivers

Demographics
1. How old are you? (Age)
2. What is your gender?
3. Could you please describe your ethnic background?
4. Could you please describe your educational background?
   a. Highest level of education you have completed/number of years of school completed
5. Are you currently employed? (Please elaborate)
   a. If you have quit (present occupation), when and why did you quit?
6. Is English your first (native) language?
7. What is your relationship status?
8. (Caregivers) Can you please tell me about your relationship to the patient?

(Patients) General Health
1. How would you describe your health in general?
2. What challenges, if any, do you face day-to-day in regards to your general health?
3. In what ways has your diagnosis affected or influenced your general health?
4. Do you have other conditions like diabetes, asthma, heart conditions, depression, anxiety, sleep problems etc.?
5. (Patients) What kind of challenges have you faced in receiving healthcare? [Probes: Have you had challenges with…] / (Caregiver) What challenges have you and the patient faced in receiving healthcare?
6. Access to healthcare/hospitals/experts
7. Travel/commute to hospitals/healthcare
8. Financial cost

Interview:

Diagnosis and Treatment

First, I would like to get to know your / the patient’s overall experience with meningioma and get a sense of the symptoms you experience / your experience as the caregiver.

Please describe:

1. (Patient) What triggered you to go see a doctor? (Caregiver) What triggered the patient to go see a doctor?
2. (Patient) When were you diagnosed with a meningioma? / (Caregiver) Can you please tell me when the patient was diagnosed with meningioma?
3. (Patient) What factor(s) do you believe caused the meningioma? / (Caregiver) What factor(s) does the patient believe caused the meningioma?
4. (Patient) Where is the meningioma located? / (Caregiver) Where is the patient’s meningioma located?

5. (Patient/Caregiver) How large is the meningioma?

6. (Patient) What effects has the meningioma had on your life / (Caregiver) What effects has the meningioma had on your life? What effects has the meningioma had on the patient’s life? [Probes – From a _____ perspective…]
   - Physical
   - Social
   - Spiritual
   - Mental
   - Emotional
   - Stress Levels

7. (Patient) What symptoms did you, and do you experience? [Probes – Did you/do you experience…] / (Caregiver) What symptoms did/do the patient report experiencing?
   - Headaches
   - Seizures
   - Fatigue
   - Weakness
   - Hearing difficulties
   - Behavioral changes
   - Cognitive deficits (memory, attention, executive function)
   - Vision problems
   - Movement problems
   - Hand arm coordination
   - Numbness
   - Difficulties walking
   - Difficulties with bodily functions (e.g. bladder)
   - Other

8. (Patient) What factors made your symptoms better, and what factors made it worse? / (Caregiver) As the caregiver, what factors have you found make the symptoms better, and what factors made them worse?

9. (Patient) What has the overall treatments been or will be? [Probes - Have you had/will you have…] / (Caregiver) What are the overall treatments that the patient has been through, or will be going through? [Probes: Has the patient had/will the patient go through…]
   a. Surgery
   b. Radiation
   c. Open procedure
   d. Chemotherapy
   e. Complementary/alternative treatments

   (Patient) If yes, can you tell me about your experience with these treatments? / (Caregiver) If yes, what was your experience with the patient going through these treatments? What was the experience like for the patient?

10. (Patient) Have you used experimental treatment or been involved in clinical trials? / (Caregiver) Has the patient been involved with any experimental treatment or clinical trial?

11. (Caregiver) Does the patient have any other conditions like diabetes, asthma, heart conditions, or depression, anxiety, sleep problems, etc.? 
12. (Patient) If you have had treatments/surgery for your meningioma, have you noticed any changes or a lack of changes in your symptoms? Please elaborate. [Probe – For example, have you experienced…] / (Caregiver) If patients have had treatments/surgery for their meningioma, have you noticed the onset of new symptoms or changes in general? Please elaborate. [Probe: For example, has the patient reported…/ as the caregiver, have you noticed…]
   a. Onset of new symptoms (if so, which symptoms?)
   b. Relief of symptoms (If so, which symptoms?)
   c. Symptoms experienced pre-surgery/treatment that continue to persist post-surgery/treatment (If so, which symptoms?)

13. (Patient) What additional things do you think your healthcare provider can do for you in terms of your diagnosis and treatment? [Probes – For example, do you think your health care provider can…] / (Caregiver) As the caregiver, what additional things do you think healthcare providers can do for the patient and family in terms of diagnosis and treatment? [Probes: For example, do you think they can…]
   a. (Patient) Prepare you better in terms of the impact of the meningioma and treatment on QOL / (Caregiver) Prepare you and the patient better in terms of the impact of the meningioma and treatment on QOL
   b. Refer/provide/explain resources (e.g. written pamphlets, resources, website), support groups, psychological support (for patients, for caregivers)
   c. Developing strategies to manage and cope with symptoms (patients and caregivers)
   d. Advocate for access to resources available (for the patients)
   e. (Caregiver) Things that the patient has brought up/you think will benefit them

Quality of Life
Second, I would like to get an overall impression of what quality of life means to you / to patients, and about how the meningioma has affected your/the patient’s quality of life.

14. (Patient/Caregiver) What does quality of life mean to you, or how do you perceive quality of life? (Caregiver) What does quality of life mean to the patient, and how do they perceive quality of life?

15. Prior to getting your meningioma, could you please describe your quality of life? [Probe: From a ___ perspective…]
   (Patient): Physical; Cognitive; Emotional; Social; Levels of stress
   (Caregiver): Physical; Social, Daily routine; Priorities/Goals; Cognitive/Mentally; Emotional; Stress Levels; Personal time

16. (Patient) How has your quality of life changed after your diagnosis? / (Caregiver) How has your quality of life changed after the patient was diagnosed with a meningioma, and after they received surgery/radiation/other treatments? [Probe: From a ___ perspective…]
   (Patient): Physical; Cognitive; Emotional; Social; Levels of stress
   (Caregiver): Physical; Social, Daily routine; Priorities/Goals; Cognitive/Mentally; Emotional; Stress Levels; Personal time
17. (Patient) How has your quality or life and daily life changed before and after:
   a. Surgery?
   b. Radiation?
   c. Other treatment?

18. (Caregiver) How would you say the patient’s quality of life changed after they have been diagnosed with a meningioma, and after they received surgery/radiation/other treatments? [Probe: From a ___ perspective...]
   a. Physical
   b. Cognitive
   c. Emotional
   d. Social
   e. Levels of stress

19. (Patient/Caregiver) Overall, has your quality of life become worse or remained the same? / (Caregiver) How about for the patient? [Probes: Please elaborate on...]
   a. Your satisfaction with your quality of life
   b. How your quality of life can be improved

20. (Patient) What factors are most important to you? [Probes: How about...]
   a. Social Relationships, physical health, goals, etc.

21. (Patient/Caregiver) Can you please tell me, in detail, about how the meningioma affected your daily life? (Caregiver) How about for the patient? [Probes: For example... ]
   a. What are some of the things you normally did daily before meningioma occurrence?
   b. How has the diagnosis affected your ability to perform day to day tasks?
   c. Your role in the family
   d. Sense of control/fulfillment in what you do

22. (Patient/Caregiver) How has your functional well-being and independence been affected? (e.g. ability to perform normal work, partake in recreational activities, self-care) / (Caregiver) How about the patient?

23. (Patient) How have you accepted your illness? / (Caregiver) Have you and the patient accepted the patient’s illness?
   Probes: How did you come to accept it / if not, why not?

24. (Patient/Caregiver) How are you sleeping? / (Caregiver) How is the patient sleeping?

Physical and Emotional Health

25. (Patient) How is your physical well-being overall? / (Caregiver) How is the patient’s overall physical health? [Probe: Would you be able to describe...]
   a. Your energy level / Their energy level
   b. If and where you experience pain / If they experience and report pain, and where

26. (Patient) What kind of physical activities can you perform? / (Caregiver) What kind of physical activities can the patient perform? [Probe: For example, can you / can the patient partake in/do...]
   a. Vigorous activities (e.g. running, lifting heavy objects, participating in strenuous sports)
b. Moderate activities (e.g. moving a table, pushing a vacuum cleaner, bowling, playing golf)

27. (Caregiver) What physical demands/changes in functioning have you experienced as a caregiver? [Probes: For example...]
   a. Changes in energy level
   b. Changes in physical ability

28. (Patient/Caregiver) Presently, how is your emotional well-being? [Probes: How do you feel/Are you...]
   (Patients) Compared to before you/the patient was/were diagnosed with meningioma; Hopefulness in fighting against meningioma; Experiencing more negative emotions after the occurrence of meningioma
   (Caregiver) Compared to before the patient was diagnosed; Do you feel hopeful in the fight against meningioma?; Your overall outlook on life; Experiencing of various emotions (e.g. frustration, helplessness, overwhelmed, anger, distress, confusion)

29. (Patient) What things worry, cause you anxiety, make you sad? / (Caregiver) What are your primary concerns, causes of worry, anxiety?
30. What brings you peace or happiness?
31. (Patient) Has your physical and well-being changed since your diagnosis, and if so, can you please explain?

Social Relationships
32. Please describe your social relationships with family, friends, and others. [Probe: How has these/the...; Tell me more about...]
   - How do these relationships affect your quality of life?
   - How close do you feel to your family? How about friends?

   (Caregivers):
   - How these relationships have changed after you became a caregiver?
   - How has it impacted your family life?

33. (Patient) Could you please describe the amount of support you receive from your family/friends/support groups? / (Caregiver) As a caregiver, what support systems are in place for you? [Probes: Tell me more about...]
   - (Patient) Do you think that your family and friends have given you enough support?
   - (Caregiver) Your self-care; What additional things you think may help you personally?

34. (Patient) How has the meningioma affected these relationships, interactions, and social life? [Probes: Can you please tell me more about... / How have the patients’ social relationships with family, friends, and others changed since the diagnosis?]
   - (Patient) How your family life has been affected by your diagnosis; Do you feel that your family has accepted your illness?
   - (Caregiver) How do these relationships affect the patient’s QOL?; How has their diagnosis impacted their relationships, interactions, social life, family life?; Do they feel
close to their friends?; Do they think that their family and friends have given them enough support?

Perspectives on providing information on personal QOL and health
35. How do you feel in regards to providing information on personal quality of life and health? [Probes: What are your thoughts on…]
   a. Providing personal information
   b. How it is shared
36. How would you like the information you shared to be protected? (e.g. masking of data, encryption, anonymization)
37. How do you feel about sharing information anonymously so people can analyze it along with data from many other anonymous patients? [Probes: For example, how would you feel about…]
   a. Data being analyzed together to improve predictions and diagnostic accuracy?
   b. Information sharing between hospitals, datasets, and databases digitally?

Other
38. Lastly, is there any additional information on how meningioma has affected your quality of life that you would like to share with us?

Thank you for your participation in this research project. Your participation is very important in finding new ways to manage meningioma. If you have any questions about our study in the future, please use the contact information on the informed consent form to get in touch with us.
Interview Guide for Healthcare Providers

Demographics
1. How old are you? (Age)
2. Could you please describe your ethnic background?
3. Could you please describe your educational background – what is the highest level of education you have completed?
4. What is your current occupation?

Interview:
Diagnosis and Treatment
First, I would like to get to know the patients’ overall experience with meningioma, and get a sense of the symptoms they experience. Based on your experience with treating meningioma patients, please describe:
1. What factors usually trigger meningioma patients to go see a doctor?
2. What are the common factors that cause a meningioma?
3. Where are meningiomas usually located and how large are they?
   - Headaches
   - Seizures
   - Fatigue
   - Weakness
   - Hearing difficulties
   - Behavioral changes
   - Cognition (memory, attention, executive function)
   - Vision problems
   - Movement problems
   - Hand arm coordination
   - Numbness
   - Difficulties walking
   - Difficulties with bodily functions (e.g. bladder)
   - Other
   - Changes in sleep patterns

5. What are the overall treatments for meningioma like? [Probe: Do patients usually receive…]
   a. Surgery
   b. Radiation
   c. Open procedure
   d. Chemotherapy
   e. Complementary/alternative treatments
6. If patients have had treatments/surgery for their meningioma, do patients typically experience changes or a lack of change in symptoms? [Probe: For example, do patients typically report…]
   - Onset of new symptoms (If so, which symptoms?)
   - Relief of symptoms (If so, which symptoms?)
   - Symptoms experienced pre-surgery/treatment that continue to persist post-surgery/treatment (If so, which symptoms?)
7. What additional things do you think healthcare providers can do for patients in terms of diagnosis and treatment? [Probes: Do you think healthcare providers can…]
   - Prepare patients better in terms of the impact of the meningioma and treatment on QOL
   - Refer/provide/explain resources (e.g. written pamphlets, resources, website), support groups, psychological support
   - Developing strategies to manage and cope with symptoms
8. What challenges do patients face in receiving healthcare? [Probes: Do patients have challenges with…]
   - Access to healthcare/hospitals/experts
   - Travel/commute to hospitals/healthcare
   - Financial cost

Quality of Life
Second, I would like to get an overall impression of what quality of life means to patients and about how meningiomas affects a patient’s quality of life.
9. What does quality of life mean to you, and how do patients usually perceive quality of life?
10. In what ways do you believe the location of the tumour affects a patient’s quality of life? [Probe]
    - Do you believe that a patient’s QOL is affected more or less depending on where their tumour is located?
11. After their diagnosis, how do patient’s quality of life change compared to before their diagnosis? [Probe: From a ___ perspective…]
    - Physical
    - Cognitive
    - Emotional (e.g. stress, satisfaction level)
    - Social
    - Better or worse
12. Could you please tell me in detail, about how meningiomas affect a patient’s daily life? [Probes: For example…]
    - How does diagnosis affect a patient’s ability to perform day to day tasks?
    - Changes in a patient’s role in the family
    - Patient’s sense of control/fulfillment in what they do
    - Post-treatment (e.g. surgery, radiation, other treatments)
13. How is a patient’s quality of life affected by the duration of the treatment? [Probe: How is their QOL affected when…]
    - The treatment is short-term
    - The treatment is long-term (more than 10 years)

Physical and Emotional Health
14. In terms of patients’ physical well-being, can you please describe the overall physical health of a patient diagnosed with meningioma? [Probe: Would you be able to describe…]
    - Their energy level?
    - Reporting/complaints of pain (location, severity)
15. What kind of physical activities can patients carry out? [Probe: For example, can patients do…]
    - Vigorous activities (e.g. running, lifting heavy objects, participating in strenuous sports)
    - Moderate activities, (e.g. moving a table, pushing a vacuum cleaner, bowling, or playing golf)
16. Can you please describe how the emotional well-being of patients are affected? [Probes]
    - How is the patient’s emotional well-being, pre-diagnosis vs. post-diagnosis?
    - Are patients’ hopeful in fighting against meningioma?
    - Do patients report feeling more negative emotions after the occurrence of meningioma
17. What are some examples of things that cause worry or anxiety for patients?
18. What brings patients peace or happiness?
19. How do patient’s physical and well-being change since their diagnosis, and if so, can you please explain?

Social Relationships
20. Could you please describe the amount of support patients receive from their family/friends/support groups?
   o How do these relationships affect a patient’s QOL?
   o Do patients think that their family and friends give them enough support?
21. How does the meningioma affect these relationships, interactions, and social life? [Probes: Can you please tell me more about…]
   o How their family life has been affected by their diagnosis?
   o Do patients feel that their families have accepted their illness?

Perspectives on providing information on personal QOL and health
22. How do you feel about patients providing information regarding their personal quality life and health? [Probes: What are your thoughts on…]
   o Providing personal information
   o How it is shared
23. How would you like information that is shared to be protected? (e.g. masking of data, encryption, anonymization)
24. How do you think patients feel about sharing information anonymously so the data can be analyzed along with data collected from many other anonymous patients? [Probes: For example, how would you feel about…]
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Other
25. Lastly, is there any additional information on how meningioma has affected patients’ quality of life that you would like to share with us?

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