Long-term experiences of living with a lower-grade glioma: a qualitative interview study

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Individual Patient Interview Guide

This is a semi-structured interview guide. Follow-up questions may be added depending on the participant's responses. The probing questions are asked when relevant and if the participant does not address the topic spontaneously.

The interviewer begins by summarising key clinical events in the participant's disease trajectory using a timeline and asks the participant to confirm its accuracy (e.g., diagnosis, surgery, initiation and completion of oncological treatment).

1. **Receiving a brain tumour diagnosis can affect many aspects of life. Can you describe how the illness has affected your life?**

2. **What symptoms have you experienced, and when did they occur?**
   Relate the participant's responses to the timeline.
   (e.g., fatigue, cognitive difficulties, emotional distress, epilepsy, physical symptoms)

   a. **How have these symptoms changed over time?**

3. **How has the illness affected your everyday life?**
   (e.g., psychological wellbeing,
   work—same job, workplace adaptations, working hours,
   relationships,
   practical support in everyday life, what support is needed, who provides it, and when the need arose)

   a. **How have you managed…?**
   b. **How do you feel about MRI follow-up examinations and your contact with healthcare in relation to these?**

4. **Has the illness influenced important life decisions? If so, how?**
   (e.g., relationships, work, having children)

5. **How do you feel that your treatments have affected you?**
   Relate the participant's responses to the timeline.

6. **What kinds of support have been valuable to you?**
   (e.g., family and friends, the neuro-oncology team, community services)

   a. **Do you feel that you received the support you needed? If not, what was lacking? What could have been done differently?**
   b. **What made the support that worked particularly valuable?**

7. **Based on your experiences today, is there anything you would have done differently during your illness trajectory?**

8. **What are your thoughts about the future?**

   a. **How have these thoughts changed since your diagnosis? Have they changed over time?**
   b. **What concerns you the most at the moment? Is there anything you are afraid of?**
   c. **Can you describe any changes you have made in planning for the future that you would not have made if you had not developed the illness?**

9. **Is there anything else you would like to add that you think is important for us to know?**