

**Appendix 1 The Cochrane library search strategy in November 2020**

Search	Query	Records retrieved
#1	glioma* OR astrocytoma OR glioblastoma OR oligodendroglioma OR ependymoma	3498
#2	caregiver OR family OR kin OR spouse OR sibling OR "significant other" OR relatives	56270
#3	"qualitative research" OR "qualitative study" OR "grounded theory" OR phenomenology	969997
#4	(glioma* OR astrocytoma OR glioblastoma OR oligodendroglioma OR ependymoma) AND (caregiver OR family OR kin OR spouse OR sibling OR "significant other" OR relatives) AND ("qualitative research" OR "qualitative study" OR "grounded theory" OR phenomenology)	7

## Appendix 2 JBI QARI Data Extraction Tool for Qualitative Research

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_

Journal \_\_\_\_\_ Record Number \_\_\_\_\_

### Study Description

Methodology|

\_\_\_\_\_

Method

\_\_\_\_\_

Phenomena of interest

\_\_\_\_\_

Setting

\_\_\_\_\_

Geographical

\_\_\_\_\_

Cultural

\_\_\_\_\_

Participants

\_\_\_\_\_

Data analysis

\_\_\_\_\_

Authors conclusions

\_\_\_\_\_

Comments

\_\_\_\_\_

Complete

Yes

No

## Appendix 3 JBI Critical Appraisal Checklist for Qualitative Research

### JBI CRITICAL APPRAISAL CHECKLIST FOR QUALITATIVE RESEARCH

Reviewer \_\_\_\_\_ Date \_\_\_\_\_

Author \_\_\_\_\_ Year \_\_\_\_\_ Record Number \_\_\_\_\_

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include  Exclude  Seek further info

Comments (Including reason for exclusion)

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Critical Appraisal Checklist for Qualitative Research - 3

## Appendix 4 Themes and Subthemes Developed from Selected Studies

### Synthesized finding 1: Role transition of caregivers for glioma patients during the disease trajectory

#### Emotional roller-coaster: psychological distress caused by the disease and the deviant behavior of the patient

- Distress, anxiety and worry from before diagnosis onwards;
- The diagnosis of a brain tumor is a shock;
- First reactions: shock and fear of death;
- Distancing;
- Fear and anxiety;
- Ambiguity: anxiety
- Extremely stressful emotions;
- Psychological distress and burden of care;
- Burden;
- The suffering of caring;
- The challenge of caring;
- Decision for surgery: helplessness or acceptance;
- First meeting with the patient after surgery: happiness or fear;
- Recognition of death;
- Deviant behavior of the patient;
- There are psychosocial effects for the caregiver, his or her family, the person with the brain tumor;
- An immediate crisis;
- A crisis delayed until the disease progresses;
- A crisis delayed until the patient returns home;
- Finding lost and alone in a new life;

#### Role negotiation: the family roles of caregivers changed

- Role negotiation;
- Role transition from family member to caregiver;
- Changed relations and roles;
- A change in relationships;
- Immediate family role changes occur;
- Renegotiating relationships;
- Developing helpful relationships;
- Relationship impacts: the experience of strengthened, maintained, or strained relations;
- Management of role and behavioral changes;
- Management of care at home;
- Management of the side effects of the tumor;
- Diagnosis and related changes in everyday life;
- Effects of the situation;
- Dependency and restricted freedom;

#### Role growth: the self-efficacy results from emotional bondage and responsibility

- Learning to be a caregiver;
- Learn to cope with the grief;
- Dealing with the situation;
- Assessment of the situation;
- Enabling strength in everyday life;
- Committedment;
- Committed but struggling to care;
- Taking responsibility;
- Recognizing the significant role of pmmt caregiver;
- Self-care;
- Prevent ill health;

#### Hope: positive life value

- Hope;
- New insight;
- Sources of power in everyday life;
- The importance of reassurance, support and hope;
- The patients and their caregivers shared hope and that the caregivers have a strong feeling of solidarity with the patient;
- Patients and caregivers towards a healthier lifestyle;
- Expectation management;
- Return to a normal life;

### Synthesized finding 2: Support and information need by caregivers of glioma patients

#### Role support is insufficient for caregivers

- Support;
- Role support;
- Social support;
- Support by others;
- Perception by others;
- Need for solid and continuous support;
- The lack of support available to caregivers;
- Meanings of support: intertwined and distinct support needs, varied expectations of support and factors influencing support expectations;
- Safe places and comfort zones;
- Being invisible and neglected;

#### The varying information needs of caregivers

- Information;
- Variations in information preferences;
- Individual strategy for acquiring prognostic information;
- Caring needs;
- Need for knowledge about managing the disease process;
- Encounter with staff;
- Threats to connecting with support;
- Practical advice and help;

**Appendix 5 The Transtheoretical Model (TTM)**  
**Adapted from: Prochaska JO, Velicer WF (1997)**

