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Mapping the Uncharted Journey: Constructing a Journey Map for Caregivers of Patients with Intracranial Tumors Based on a Systematic Review of Qualitative Research

Fei NI
First Hospital of China Medical University
Yang LIU
First Hospital of China Medical University
Xutong ZHENG
First Hospital of China Medical University
Hui SUN
First Hospital of China Medical University
Jinan FANG
First Hospital of China Medical University
Aiping WANG
apwang@cmu.edu.cn

First Hospital of China Medical University

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Abstract

Objective

This study aims to synthesize qualitative evidence to construct a journey map delineating the experiences and needs of caregivers of patients with intracranial tumors.

Methods

A systematic literature search was conducted across six electronic databases (PubMed, Web of Science, CINAHL, EMBASE, Scopus, and PsycINFO) from their inception to December 2025, supplemented by manual searches of reference lists from relevant articles.This review focused on the lived experiences, perceptions, unmet needs, and emotional states of informal caregivers of individuals with intracranial tumors.Two researchers independently screened the literature and assessed the methodological quality of included studies using the Critical Appraisal Skills Programme tool for qualitative research.Data extraction was then performed to collate pertinent information, and thematic analysis was employed to summarize and synthesize the findings from the included studies.This qualitative systematic review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement.

Results

This review included 18 articles and constructed a caregiver journey map encompassing six sequential phases: screening and diagnosis phase, perioperative period, continuing treatment phase, disease progression phase, hospice care phase, and bereavement and reconstruction phase.This journey map systematically delineates the core tasks, emotional experiences, primary pain points, potential opportunity points, and relevant stakeholders for caregivers at each phase.

Conclusion

The caregiver journey map for patients with intracranial tumors developed in this study innovatively integrates the complex experiences and needs of caregivers across the entire disease trajectory in a visual and phased manner.This map provides a structured toolkit for clinical healthcare professionals, offering an evidence-based foundation for future clinical practices such as phased supportive needs assessment, multidisciplinary collaboration, implementation of precise supportive interventions, and optimization of continuous care services. Furthermore, it establishes an evidence-informed framework for healthcare and education administrators as well as policymakers to optimize resource allocation and design continuous support services.

Background

Intracranial tumors, as a category of neurological diseases characterized by high incidence, mortality, and disability rates, have become a significant global public health challenge[1–3]. These conditions not only impose severe physical and psychological impacts on patients but also place substantial disease burdens and economic pressures on their families and the broader healthcare system[4,5]. With advances in diagnostic and therapeutic technologies, patients' survival periods have been extended, meaning their families often face a longer, more complex, and uncertain caregiving journeytime. Throughout this process, family caregivers play an indispensable and central role. They typically assume multiple responsibilities: serving not only as daily care providers and participants in medical decision-making but also as collaborators in rehabilitation efforts and crucial communication bridges between patients and the healthcare system[6–8]. However, this central role also exposes caregivers to a context of multidimensional stressors. They must simultaneously manage high medical and financial burdens, maintain routine family functions, coordinate personal career development, and navigate dynamic adjustments in family roles and relationships[9–11].Remaining in such a high-stress state over the long term often results in caregivers' physical and mental health needs being overlooked or deprioritized, which can trigger a range of long-term health impairments, including anxiety, depression, post-traumatic stress disorder (PTSD), and chronic physical fatigue[12–15]. Additionally, caregivers often suppress their own grief and exhaustion in front of patients, consistently presenting a positive and stable emotional state to serve as an emotional anchor for the patient. This emotional management consumes considerable psychological energy and lacks appropriate outlets for release, leading to an accumulation of emotional burden[16].At the family and societal levels, primary caregivers may experience conflicts with relatives due to inequitable distribution of caregiving responsibilities, or become socially isolated as they gradually disengage from their original social networks after prolonged focus on caregiving[17]. On the practical front of caregiving, they must also navigate complex tasks such as understanding specialized medical terminology, evaluating different treatment options, and handling medical reimbursement procedures. The challenges of information asymmetry and the significant responsibility of decision-making often leave them feeling inadequately informed and overwhelmed, especially when facing major medical choices where they carry heavy ethical and emotional burdens [18].Therefore, gaining an in-depth understanding of the holistic challenges caregivers face in this complex caregiving context, the mechanisms through which stressors operate, and their specific support needs—and subsequently developing systematic and effective multidimensional support strategies—holds important theoretical and practical significance for alleviating caregiver burden, improving the quality of family care, and enhancing patient outcomes.

In recent years, the burden and needs of caregivers for patients with intracranial tumors have gradually garnered academic attention. Existing studies have widely revealed that this group has significant and unmet needs in areas such as information acquisition, caregiving skills, psychological support, and access to social resources[19,20]. However, much of this research has certain limitations: it often focuses on specific phases such as the perioperative or end-of-life phases, while relatively neglecting other critical stages within the prolonged disease course, such as the continuation treatment phase and disease

progression phases[21–23]. This phase-specific focus fails to fully capture the genuine picture of how caregiver burden and needs dynamically evolve along the disease trajectory. In contrast, within other chronic disease fields, research adopting a "whole-course, stage-specific" approach to explore caregiver experience is already relatively common[24,25]. Currently, there is a lack of an integrated framework capable of holistically depicting the dynamic evolution of intracranial tumor caregivers' experiences, and a failure to systematically elucidate the key challenges, critical transition points, and corresponding potential support pathways at different stages. The absence of this holistic perspective hinders the effective development and implementation of targeted, continuous support intervention systems and public health policies.

Journey mapping, as a systematic visualization tool, is commonly used to describe and evaluate an individual's overall experience within a healthcare process. It presents an individual's behaviors, perceptions, and feelings throughout their medical journey in a phased and contextualized manner[26]. The strength of journey mapping lies in its robust potential for synthesis and insight generation. It can integrate fragmented evidence to synthesize findings from heterogeneous studies into a coherent, holistic narrative framework[27]. Furthermore, it is capable of identifying key caregiver pain points, clearly revealing the core challenges and supportive care needs they face across different stages of care[28]. Currently, journey mapping has been widely applied in fields such as gestational diabetes[29], cardiovascular and cerebrovascular diseases[30,31], sleep disorders[32] disability[33], and infectious diseases[34]. Within caregiver research specifically, existing literature indicates that the journey mapping method has been preliminarily applied to depict the caregiving trajectory of caregivers for patients undergoing total knee arthroplasty[35] and the psychological and social adaptation journey of partners in high-risk pregnancies[36]. However, a systematic literature review reveals that few studies have applied journey mapping to depict the experiences of the specific population of caregivers for patients with intracranial tumors.

From this methodological perspective, this study aims to systematically synthesize qualitative evidence to construct a clearly defined caregiver journey map. This map will systematically delineate the tasks undertaken, emotional fluctuations, core pain points, and potential intervention opportunities for caregivers across distinct stages, including the screening and diagnosis phase, perioperative period, continuation treatment phase, disease progression phase, end-of-life care phase, and the bereavement and reconstruction phase. It will also identify the key stakeholders involved and their patterns of interaction at each stage. By systematically visualizing this journey, the map will intuitively reveal the dynamic evolution of caregiver experiences and their stage-specific needs. This will provide a robust empirical foundation for developing stage-specific personalized support programs, formulating targeted public health and policy initiatives, guiding educational reforms, and planning future longitudinal research. Ultimately, the goal is to enhance the overall well-being of family caregivers and improve the quality of care for patients with intracranial tumors.

Design and methods

Study design

This systematic review is reported in accordance with the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guidelines[37] and strictly adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement[38]. Furthermore, the study protocol has been prospectively registered with the International Prospective Register of Systematic Reviews (PROSPERO) under registration number CRD420251244021.

Data sources and search strategy

The search strategy was pre-defined by the research team. We conducted computerized searches in PubMed, Web of Science, Scopus, Embase, CINAHL, and PsycINFO. The search was limited to articles published from the inception of each database until December 2025. A snowball search was performed on the reference lists of included studies and relevant systematic reviews. Boolean logic was employed to combine Medical Subject Headings (MeSH) terms and keywords. The search strategy comprised three categories of terms: intracranial tumors, caregivers, and qualitative research. The complete search strategy is available in Supplementary File 1.

Study selection

We developed the inclusion and exclusion criteria for the study based on the PICOS framework (Table 1)[39].

Table 1
Inclusion and exclusion criteria for studies.

Items	Inclusion criteria / exclusion criteria
Inclusion criteria	
P-Population	Informal caregivers of patients with intracranial tumors are defined as family members, partners, relatives, or friends (aged ≥ 18 years) who provide unpaid daily care, emotional support, or practical assistance to patients with intracranial tumors.
I-Intervention	The experiences, perceived needs, and feelings of informal caregivers of patients with intracranial tumors.
C-Context	The experiences of informal caregivers of patients with intracranial tumors can occur in any setting, such as the home, hospital, nursing home, hospice, or long-term care facility.
O-Outcome	The experiences, perspectives, and needs of informal caregivers of patients with intracranial tumors.
S-Study design	Any qualitative study, including but not limited to phenomenology, ethnography, descriptive qualitative research, grounded theory, and mixed-methods designs; for mixed-methods studies, only the qualitative components were included.
Exclusion criteria	
(1) Studies in which the experiences of informal caregivers of patients with intracranial tumors are mixed with those of the patients and cannot be clearly distinguished.	
(2) Studies from which qualitative data cannot be extracted.	
(3) Studies not published in English.	
(4) Books or book chapters, essays, theses or dissertations, commentaries, and conference abstracts.	

Data extraction

Search results were exported from the electronic databases to EndNote X21. After removing duplicate citations, two authors (NF and LY) independently screened the titles and abstracts against the eligibility criteria. If the information in the title and abstract was ambiguous, the full text of the article was reviewed to determine its eligibility. Studies meeting the inclusion criteria underwent a full-text review. Following full-text screening, a total of 18 studies met the final inclusion criteria. At each stage, records were independently reviewed by the two authors (NF and LY). Disagreements were resolved through discussion within the research team, and reasons for exclusion were documented.

Risk of bias assessment

The quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist[40]. The appraisal results were verified by two authors (NF and LY), with a third author (XT) available to resolve any conflicts. This checklist comprises ten criteria: clarity and appropriateness of the research aims, methodology, research design, recruitment strategy, data collection, the relationship between researchers and participants, ethical considerations, data analysis, findings, and the value of the research. Each criterion requires a response of "yes," "no," or "cannot tell." This tool enabled a thorough familiarization with the content of the papers and established a foundation for assessing the methodological limitations of the findings synthesized in this review.

Data extraction process

Following a comprehensive full-text review, two researchers extracted the relevant information required for this systematic review into a pre-structured Excel spreadsheet. The extracted information primarily included the author(s)' name(s), year of publication, study objectives, patient characteristics, caregiver characteristics, recruitment settings and sample sampling methods, research methods, analytical methods, and main findings.

We employed thematic analysis to conduct an in-depth exploration of the interview data. The data synthesis followed the three-stage thematic synthesis method proposed by Thomas and Harden[41]. In the first stage, two researchers independently reviewed the articles and performed line-by-line coding using NVivo V.12.0, focusing on the authentic experiences, underlying needs, and feelings of intracranial tumor caregivers. The coded data were subsequently subjected to collective reflection and discussion. In the second stage, the independent codes were grouped into descriptive themes. The researchers then cross-checked and discussed these groupings to minimize subjective bias and conceptual redundancy among the codes, ensuring the themes accurately represented the included studies. To ensure reliability, the researchers regularly reviewed and discussed coding consistency. In the final stage, overarching analytical themes were developed from the descriptive themes. Based on these synthesized analytical themes, a journey map was created to analyze the experiences and perceptions of intracranial tumor caregivers throughout the entire caregiving trajectory.

Results

Search and selection results

A comprehensive search across six English-language electronic databases yielded a total of 18,518 studies. Among these, 4,233 records were identified as duplicates and subsequently removed. After screening titles and abstracts, 14,167 articles were excluded based on the eligibility criteria, leaving 118 articles

selected for full-text review. For various reasons, 100 articles were excluded (Fig. 1). A manual search of the reference lists of relevant articles did not identify any additional eligible studies. Consequently, 18 articles were ultimately included in this meta-synthesis.

Study characteristics

Among the 18 studies included in this review, 17 employed a qualitative design, and 1 utilized a mixed-methods design. Of the 17 qualitative studies, the designs comprised descriptive qualitative research (n = 7), phenomenological research (n = 5), and grounded theory research (n = 5). The specific qualitative methodology within the mixed-methods study was not explicitly stated. Regarding data analysis, thematic analysis was applied in 15 studies, while content analysis, phenomenological hermeneutics, and the constant comparative method derived from grounded theory were each employed in one study, respectively.The included articles were published between 2008 and 2025. The sample sizes in these studies ranged from 6 to 92 caregivers, with ages spanning from 18 to 84 years. In the studies included in this review, the majority of caregivers (79.9%) were spouses of the patients, while 20.1% comprised the patients' parents, children, other relatives, or friends.The studies were conducted across eight countries. Over 50% of the included studies were concentrated in European countries, including the United Kingdom (n = 3), Denmark (n = 3), Turkey (n = 1), Belgium (n = 1), and Sweden (n = 1). The remaining studies were conducted in North America, comprising the United States (n = 3) and Canada (n = 1), and in Oceania, specifically Australia (n = 4). One additional study was conducted jointly in Australia and Denmark.Study characteristics are summarised in Table 2.

Table 2
Characteristics of included studies.

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
Schmer 2008[42]	United States	To explore the caregiver perspective of providing care during the initial 6 months of chemotherapy treatment for a primary malignant brain tumor.	Type of intracranial tumor: Primary malignant brain tumor (e.g., astrocytoma, glioblastoma). Age and gender: Were not reported in the study.	Sample Size: N = 10 Age, Gender: Not reported. Relationship to Patient: spouse (n = 7), daughter (n = 2), and son-in-law (n = 1).
Schubart 2008[43]	United States	Research on the specific challenges faced by family caregivers in caring for brain tumor patients, including caregiving tasks, decision-making, and information and support needs.	Type of intracranial tumor: Primary brain tumor (e.g., Glioblastoma, Anaplastic oligoastrocytoma, etc.) Age range: 20–70 + years Gender: Not reported	Sample Size:N = 25 Age range: 37–72 years Gender: 18 females, 7 males Relationship to patient: spouse (n = 18),parent(n = 4), children(n = 2), sibling(n = 1).

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
McConigley 2010[44]	Australia	To articulate the experiences of family caregivers of people diagnosed with high-grade glioma. To describe the information and support needs of these family caregivers.	Type of intracranial tumor: Astrocytoma Grade 3–4 And Glioblastoma multiforme Age range: 30–39 (n = 1), 40–49 (n = 3), 50–59 (n = 9), 60–69 (n = 5), 70+ (n = 2), Missing data (n = 1) Gender:Male (n = 16), Female (n = 5)	Sample Size: N = 21 Age range: 30–39(n = 2),40–49(n = 2),50–59(n = 10),60–69(n = 6),70+: (n = 1) Gender:Male(n = 4); Female(n = 17) Relationship to Patient: Spouse/partner: (n = 20),Parent(n = 1)
Tastan 2011[45]	Turkey	To determine and classify the experiences of the relatives of patients who underwent cranial surgery for a brain tumor during the perioperative period and home care.	Type of intracranial tumor: Glioblastoma,Astrositoma,Schwannoma,Oligodendrioglioma,Pituitary adenoma Age range: Mean ± SD: 40.1 ± 15.4 years Gender:Male (n = 6), Female (n = 4)	Sample Size: N = 10 Age range: Mean ± SD:38 ± 9.95 years Gender:Male(n = 4); Female(n = 6) Relationship to Patient: Spouse (n = 4), Offspring (n = 4), Parent (n = 1), Sibling (n = 1)
Shortman 2013[46]	United Kingdom	1.To explore the impact of having a child with a brain tumour on the main caregiver in the family.	Type of intracranial tumor: Not explicitly specified in the study Age range: 8–13 years,Median age: 10.5 years Gender:Male (n = 4), Female (n = 2)	Sample Size: N = 6 Age range: Not reported Gender: Female

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
		2.To describe mothers' experiences of coping with their child's illness, including personal barriers and strengths. 3.To identify causes of stress and sources of support to inform improvements in care delivery.		Relationship to Patient: mothers
Collins 2014[47]	Australia	1.To provide an in-depth exploration of the needs and concerns of people caring for patients with primary malignant glioma (PMG). 2.To develop greater understanding of these care needs during the patient's palliative illness phase. 3.To obtain insight into bereaved family members' experiences of caring for someone with PMG.	Type of intracranial tumor: High-grade primary malignant glioma (PMG grades III–IV) Age and gender: Were not reported in the study.	Sample Size: N = 23 Age range: 27 years to 77 years (median 54 years) Gender:Male(n = 9); Female(n = 14) Relationship to Patient:Spouse/partner (n = 17), Child (n = 4), Other (n = 2)
Coolbrandt 2015[48]	Belgium	1.To explore the experience of family caregivers of patients with high-grade glioma (HGG). 2.To identify family caregivers' needs related to professional care.	Type of intracranial tumor: High-grade glioma (HGG) Age and gender: Were not reported in the study.	Sample Size: N = 16 Age range: Mean 54.2 years (range 31–68 years) Gender:Male(n = 6); Female(n = 10) Relationship to Patient:partner (n = 13), Parents (n = 2), Friend (n = 1)

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
Piil 2018[49]	Denmark	To explore the perspectives of newly bereaved caregivers to patients with high-grade glioma (HGG) regarding end-of-life (EOL) caregiving and their bereavement experiences.	Type of intracranial tumor: High-grade glioma (HGG): glioblastoma anaplastic astrocytoma (AA) grade III Age range:50–68 years old Gender: Were not reported in the study.	Sample Size: N = 8 Age range: Mean 48 years (range not fully specified, individual ages 28–60 years) Gender:Male(n = 6); Female(n = 10) Relationship to Patient:Wife (n = 4), Husband (n = 1), Son (n = 1), Daughter (n = 1)
Francis 2020[50]	Denmark	To explore ethical dilemmas spouses experience in the everyday care of a partner in treatment for primary malignant brain tumour.	Type of intracranial tumor: Primary malignant brain tumour (PMBT). Age and gender: Were not reported in the study.	Sample Size: N = 10 spouses Age range: 36 to 76 years. Gender:Male(n = 3); Female(n = 7) Relationship to Patient:Spouses
Kirby 2022[51]	Australia	To better understand the everyday experiences of home-based informal caregivers of people living with glioma in Queensland, Australia, and explore how the various experiences, demands, and social and relational dynamics in/of informal care (re)produce forms of isolation and loneliness.	Type of intracranial tumor: Glioma Age range:24 to 84 years Gender: Were not reported in the study.	Sample Size: N = 32 Age range: 18 to 84 years. Gender:Male(n = 11); Female(n = 21) Relationship to Patient:Partners (n = 17), parents (n = 5), children (n = 4), siblings n=(2), friends (n = 4).
Francis 2022[52]	Denmark	To investigate spouses' experiences of suffering in their role as main caregiver of a partner with primary malignant brain tumor (PMBT).	Type of intracranial tumor: Primary malignant brain tumor (PMBT). Age range And Gender: Were not reported in the study.	Sample Size: N = 10 spouses. Age range: 36 to 76 years. Gender:Male(n = 3); Female(n = 7)

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
				Relationship to Patient:Spouses
Sayal 2023[53]	Canada	To explore the experience of parental caregivers caring for medulloblastoma survivors, including family experiences, social circumstances, and family-reported impact.	Type of intracranial tumor: Medulloblastoma Age range:Median age at diagnosis was 7 years (range: 1–9 years); median age from treatment at interview was 9.5 years (range: 5–12 years). Gender:Male(n = 12); Female(n = 8).	Sample Size: N = 20 Age range: Were not reported in the study. Gender:Male(n = 15); Female(n = 5) Relationship to Patient:Parental caregivers

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
Rimmer 2024[16]	United Kingdom	To explore the emotional impact of informal caregiving for people with lower-grade gliomas (LGGs), including experiences related to the illness, uncertain prognosis, care recipient changes, and caregiving responsibilities.	Type of intracranial tumor: Lower-grade gliomas (grade 2 astrocytoma, grade 2 or 3 oligodendroglioma). Age range:mostly in their 30s and 40s And Gender:Were not reported in the study.	Sample Size: N = 19 Age range: Mean age 54.6 years (range 36–78 years) Gender:Male(n = 5); Female(n = 14) Relationship to Patient:spouses(n = 15),sisters(n = 2), mothers(n = 2).
Clarke 2024[54]	Australia	(i) To explore what carers of people with high-grade glioma (HGG) perceive could improve their preparedness to care; (ii) To identify what needs carers reported they required additional support with.	Type of intracranial tumor: High-grade glioma (HGG), encompassing grade III and IV glioblastoma. Age range And Gender: Were not reported in the study.	Sample Size: N = 92 Age range: Were not reported in the study. Gender:Male(n = 18); Female(n = 74) Relationship to Patient:Spouses/partners accounted for the majority (89%, 82/92)

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
McDougall 2025[55]	Australiaand Denmark	Primary objective: To explore the unspoken, taboo thoughts and difficult emotions experienced by carers supporting individuals with brain tumour-related personality and behaviour changes. Secondary objective: To examine the coping strategies used by these carers.	Type of intracranial tumor: Primary malignant brain tumour (PMBT), including glioblastoma (12 cases), astrocytoma (1 case), oligodendroglioma (1 case); tumour grade III (6 cases) and IV (8 cases). Age range: Australia (mean: 55 years, range: 45–65 years); Denmark (mean: 53 years, range: 44–66 years). Gender:Were not reported in the study.	Sample Size: N = 13 Age range: 42–68 years Gender:Male(n = 1); Female(n = 12) Relationship to Patient:Spouses(n = 12), sibling(n = 1)

Authors	Countries	Objectives	Patient characteristics	Caregiver characteristics
Muasher-Kerwin 2025[56]	United States	To investigate the perspectives of family caregivers of glioblastoma multiforme (GBM) patients, focusing on the barriers and challenges they encounter when providing care.	Type of intracranial tumor: Glioblastoma multiforme (GBM) Age range And Gender:Were not reported in the study.	Sample Size: N = 19 Age range: 25–78 years, average 56 years; 31.6% in 65–74 age group. Gender:Male(n = 5); Female(n = 14) Relationship to Patient: Wife (n = 10), husband (n = 3), daughter (n = 3), son (n = 1), father (n = 1), sister (n = 1).
Zanotto 2025[17]	United Kingdom,United States	To understand the informal caregivers' lived experiences of coping, support needs, and changes in relationships while caring for a family member or friend with a primary brain tumor.	Type of intracranial tumor: Primary brain tumor (low-grade, high-grade, unknown grade; including grade 2, 3, 4 tumors). Age range: 20–82 years Gender:Were not reported in the study.	Sample Size: N = 10 Age range: 19–68 years Gender:Male(n = 1); Female(n = 9) Relationship to Patient: Spouses/partners (n = 3), parents (n = 4), adult children (n = 2), sibling (n = 1).
Neander 2025[57]	Sweden	To investigate relatives' experiences of living close to an adult with low-grade glioma (LGG, grade 2) and explore how the disease impacts daily life and the relationship with the patient over time through repeated interviews.	Type of intracranial tumor: Low-grade glioma (grade 2), including astrocytoma II, oligodendroglioma II-III, oligoastrocytoma II; some with no histology data. Age range And Gender:Were not reported in the study.	Sample Size: N = 15 Average age: 47 years Gender:Male(n = 6); Female(n = 9) Relationship to Patient: Spouse/partner (n = 11), parents (n = 2), siblings (n = 2)

Quality of the included studies

Overall, the included studies demonstrated sound methodological quality across multiple key dimensions. All studies clearly stated their research aims and employed qualitative methodologies and appropriate research designs that aligned with their research questions. The data collection processes were consistently reported as appropriate and well-documented, and ethical considerations were explicitly addressed in all studies. Regarding findings and research value, all studies presented their results clearly with supporting evidence and were assessed as contributing value to either practice or the research field.The appraisal also identified areas for potential improvement. Transparency in participant recruitment strategy was insufficiently described in several studies[42,45,46,49,50,52,54]. A number of studies did not adequately discuss the researcher-participant relationship and potential issues of reflexivity (rated as "NO" [42,45,49,54]; rated as "Can't Tell"[47][16,17,44,46–48,53,56]). Additionally, the rigor of the data analysis process was not described in sufficient detail in a few studies[42,44–46]. (Table 3).

Table 3
Critical appraisal skills programme (CASP) checklist for included articles.

Articles	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. I rese valu
Schmer etal.(2008) [42]	Yes	Yes	Yes	NM	Yes	NO	Yes	NM	Yes	Yes
Schubart etal.(2008) [43]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
McConigley etal.(2010) [44]	Yes	Yes	Yes	Yes	Yes	NM	Yes	NM	Yes	Yes
Tastan etal. (2011)[45]	Yes	Yes	Yes	NM	Yes	NO	Yes	NM	Yes	Yes
Shortman etal.(2013) [46]	Yes	Yes	NM	NM	Yes	NM	Yes	NM	Yes	Yes
Collins etal. (2014)[47]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Coolbrandt etal.(2015) [48]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Piil etal. (2018)[49]	Yes	Yes	Yes	NM	Yes	NO	Yes	Yes	Yes	Yes
Francis etal.(2020) [50]	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes	Yes	Yes
Kirby etal. (2022)[51]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Francis etal.(2022) [52]	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes	Yes	Yes
Sayal etal. (2023)[53]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Rimmer etal.(2024) [16]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Clarke etal. (2024)[54]	Yes	Yes	Yes	NM	Yes	NO	Yes	Yes	Yes	Yes
McDougall etal.(2025) [55]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Muasher-Kerwin etal. (2025)[56]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Zanotto etal.(2025) [17]	Yes	Yes	Yes	Yes	Yes	NM	Yes	Yes	Yes	Yes
Neander etal.(2025) [57]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

NM = Not Mentioned

Journey Map Construction

Journey maps typically consist of a horizontal axis (timeline) and vertical axes (dimensions of activities)[58]. In this study, the horizontal axis represents the various stages and touchpoints in the caregiving journey for intracranial tumor caregivers. The vertical axes were constructed based on the research objectives, encompassing the tasks, emotions, pain points, opportunities, and stakeholders involved in the caregiving journey for intracranial tumor patients. Figure 2 illustrates the full disease-course experience journey of caregivers for patients with intracranial tumors. This map was constructed based on the

thematic synthesis results of the 18 included qualitative studies. Through systematic review and inductive analysis, we identified six consecutive stages in the caregiver journey from screening and diagnosis to bereavement and reconstruction: the screening and diagnosis phase, perioperative period, continuation treatment phase, disease progression phase, end-of-life care phase, and the bereavement and reconstruction phase. This stage division closely aligns with the key clinical turning points in the trajectory of intracranial tumors and the evolution of caregiving tasks. Furthermore, this journey map not only provides healthcare professionals with an evidence-based reference that is both broadly applicable and context-specific but also serves as an integrated, structured visual tool. This facilitates the implementation of stage-sensitive assessments and targeted support in clinical practice.

Screening and Diagnosis Phase

The screening and diagnosis phase marks the initial stage of the caregiver's journey, characterized predominantly by intense emotional upheaval and a high demand for information processing. Upon receiving the diagnosis, caregivers commonly experience shock, fear, and helplessness, often accompanied by recurring questions of "why us" [42,45,46]. Non-empathetic medical communication can exacerbate emotional distress, potentially causing secondary psychological trauma[45,48]. In response to this crisis, caregivers typically engage swiftly in a series of critical tasks: accompanying the patient to medical appointments, organizing medical history, comprehending medical information, seeking second opinions, and undertaking the difficult task of explaining the condition to other family members. During this process, they frequently face ethical dilemmas between "protecting the patient" and "disclosing the full truth" [42,44]. Some caregivers may choose to temporarily withhold the diagnosis from the patient to buffer the emotional impact[42].The core pain points in this phase center on caregivers' often unmet needs for clear diagnostic information, decision-making support, guidance on role transition, and early psychological support[45]. The abrupt role shift and emerging financial pressures intensify their confusion and burden. Feelings of weakened social connections and interrupted future plans are particularly pronounced[43,48].Consequently, key intervention opportunities in this stage lie in the healthcare system proactively providing clear and empathetic diagnostic communication and promptly referring caregivers to psychological support networks and financial aid services. This approach aims to establish a starting point for the long-term caregiving journey that is equipped with resources and emotional support, thereby mitigating the psychosocial risks during this critical period of role transition [42,45].

Perioperative Period

The perioperative period signifies a fundamental shift in the caregiver's role identity, transitioning from an auxiliary decision-maker to the primary responsible party undertaking practical caregiving tasks. During this phase, caregivers are required to participate in surgical decision-making, sign informed consent forms, coordinate hospitalization logistics, and begin learning postoperative care knowledge and rehabilitation skills[45,54].Upon first seeing the patient after surgery, caregivers' emotions often oscillate between relief and uneasiness: comforted by the patient's survival yet potentially shocked by changes in their appearance or condition. This moment also marks the beginning of their awareness that the surgery may result in irreversible neurological deficits, triggering anxiety about long-term rehabilitation[45]. In terms of actions, caregivers focus on providing emotional support during hospitalization, assisting with early rehabilitation, advocating for the patient's rights, and maintaining close communication with the medical team[43].The core pain points in this stage lie in the caregivers' common lack of sufficient care-related knowledge and skills, and inadequate information regarding the surgery and postoperative care. They simultaneously endure significant psychological and role-related stress, alongside markedly increased time and financial burdens[43,52].Corresponding support opportunities include: systematically providing caregivers with education and training related to surgery and nursing to enhance their caregiving capacity; offering psychological support to alleviate emotional distress; and tangibly reducing their multifaceted burdens by coordinating in-home assistance, facilitating flexible work arrangements, providing financial subsidies, and maintaining open communication channels with the healthcare team[45,54].

Continuation Treatment Phase

The continuation treatment phase signifies the caregiver's entry into a phase of long-term management, characterized by the routinization and increasing complexity of care work. During this stage, the caregiver's core tasks shift towards managing treatment side effects, supervising medication adherence, arranging and accompanying follow-up visits, and striving to adapt to new family roles and divisions of labor while undertaking substantial daily care[44,50].Caregiver behavior manifests as a multi-layered coping system: systematically managing daily affairs such as transportation, meals, and work at the life-management level; directly handling disease- or treatment-induced behavioral and cognitive changes at the clinical-coping level; and actively seeking and integrating external support at the resource-coordination level. Notably, to maintain the stability of the care system, caregivers frequently suppress their own emotions, which has become a significant psychological and behavioral characteristic[44,48].Prolonged stress and role burden trigger distinct emotional responses, including fatigue stemming from physical and mental exhaustion, loneliness due to reduced social interaction and a lack of understanding, and the alternating feelings of hope and frustration amidst fluctuating clinical conditions, often accompanied by guilt and self-doubt[16,48].These challenges reflect the core pain points of this stage: caregivers commonly experience insufficient caregiving capacity, particularly in managing neurocognitive and behavioral symptoms[47]; their social support networks are weak, and their own health is severely neglected[50]; furthermore, persistent financial and occupational pressures constitute a significant real-world burden[43].Corresponding support opportunities include: constructing a professionalized support system, such as developing individualized care plans and forming multidisciplinary teams[54]; providing substantive assistance like respite care, household help, and financial and workplace support; establishing an ongoing psychological support network through means such as support groups; and actively guiding and encouraging caregivers to engage in necessary self-care[50,53].

Disease Progression Phase

The disease progression period represents a challenging transitional stage in the caregiver's journey, characterized by significant deterioration in the patient's condition and a fundamental shift in caregiving goals. During this phase, the caregiver's tasks become exceptionally burdensome and complex, primarily involving participation in palliative care decision-making, closely monitoring and managing symptom exacerbations, promptly adjusting care plans, and coordinating multidisciplinary medical and care resources[51,54].Caregivers face markedly increased intensity and complexity in care provision. They must not only respond to rapidly evolving clinical changes but also strive to manage more challenging neurobehavioral symptoms, such as aggressive behaviors, which may even lead caregivers to feel as though they are in a "domestic violence relationship"[55]. This series of challenges triggers profound and complex

emotional responses: pervasive grief and despair, fear and anxiety about the patient's impending death, and, due to prolonged high stress, physical and emotional exhaustion. Caregivers may develop thoughts wishing for the patient's "early release," which conflict with their ethical role, causing intense emotional self-reproach and placing their emotions in a state of contradiction and conflict during this phase[47,55]. The cumulative physical and psychological burden on caregivers gradually peaks in this stage, manifesting in significant somatic symptoms[49].The core pain points of this stage are concentrated in the following areas: the economic burden stemming from long-term care further diminishes the caregiver's coping capacity[54]; a lack of systematic and continuous psychological support resources exacerbates emotional exhaustion[49]; and caregivers endure immense physical and psychological pressure at critical medical decision-making junctures, such as palliative care transitions[56].Corresponding support opportunities should include: promoting early palliative care intervention to optimize symptom management and care goals[47]; providing caregivers with continuous psychological support and necessary financial assistance[53]; and enhancing the role of care coordinators to systematically alleviate the burden of care management for caregivers[54].

End-of-Life Care Phase

The end-of-life care phase marks a fundamental transformation in the caregiver's role, with the core objective shifting from a treatment-centric focus on prolonging life to a patient-centric commitment to ensuring comfort and dignity during the final stage of life. In this terminal phase, the caregiver's central tasks concentrate on providing comprehensive comfort care, making difficult decisions regarding the limits of treatment, and offering continuous presence and support through the final farewells[49,54].Specific behaviors include delivering close bedside care, facilitating crucial conversations—such as assisting the patient in expressing final wishes or completing advance care planning documents through guided communication—, communicating with the medical team to discontinue aggressive interventions, coordinating various hospice services, and potentially seeking spiritual support or arranging religious rituals to provide solace for both the patient and the caregiver[46,51].This process is accompanied by an exceptionally complex wave of emotions: intense sorrow and grief form the predominant tone, interwoven with guilt over decisions made, and a sense of relief at the end of suffering following prolonged exhaustion[49,51].The core pain points of this stage lie in the immense decisional pressure concerning critical issues such as life support[55] and the dual emotional burden caregivers must shoulder—managing their own profound grief while also navigating additional strains arising from family dynamics[49].Corresponding support opportunities should focus on providing systematic humane care, including the early introduction of professional hospice services[49]; offering clear guidance on end-of-life decision-making and sustained psychological support for caregivers[54]; providing spiritual care; and proactively initiating bereavement support to prepare caregivers for a smoother transition into the subsequent phase of loss[53].

Bereavement and Reconstruction Phase

The bereavement and reconstruction period signifies the prolonged process through which the caregiver, following the patient's death, transitions from the role of caregiver to that of a mourner and ultimately attempts to reintegrate into social life. The core tasks of this stage include processing and integrating complex grief, arranging funerals and posthumous matters, replanning personal life in the reality of loss, and actively seeking necessary psychological and social support [49,53].The death of the loved one signifies that the anticipatory grief long carried by the bereaved person materializes from a state of suspended psychological preparation into the lived experience of loss and an ongoing mourning process[17]. The mourning of the bereaved exhibits a composite structure: their grief is directed not only towards the deceased loved one but also extends to the loss of their own social identity attached to that relationship, such as being a spouse or parent, and the shared life vision that was co-constructed within that relationship but vanished with the disease progression [50,55].Their behaviors show a progressive shift from mourning to reconstruction, typically including participation in farewell rituals, sorting through belongings to process emotional attachments, seeking psychological counseling or joining bereavement support groups to channel emotions, and gradually resuming social and occupational activities to rebuild life order and achieve financial autonomy [46,51,53].This stage is accompanied by contradictory and dynamic emotional changes: initial intense sorrow and longing are often followed by feelings of relief and release due to the lifting of caregiving pressures, which may then give way to loneliness and identity crisis stemming from the sudden void in life[17,49]. Finally, through gradual adjustment, some individuals may begin to rediscover hope for the future, experiencing a sense of "rebirth"[46,51].The core pain points of this stage lie in the general lack of systematic grief support systems within society, leading to unaddressed emotional trauma for many[53]. Individuals who have lost their caregiving role face severe challenges in life reconstruction and identity crisis, which to some extent exacerbates social isolation[17]. Furthermore, the financial pressures accumulated from long-term treatment and care during the patient's life often persist after their death in forms such as outstanding debts, further intensifying the difficulties faced during this transitional phase[49].Therefore, key support opportunities involve building a continuous support system, including providing professional grief counseling and bereavement support groups[53]; assisting in developing personalized life reconstruction plans and offering re-employment guidance to facilitate social reintegration[49]; encouraging the participation of the bereaved in community activities to rebuild social connections and mitigate isolation; and ensuring the accessibility of long-term, professional psychological services for the early identification and intervention of potential prolonged grief disorder[17].

Discussion

Construction of the Intracranial Tumor Caregiver Journey Map and its Implications for the Support System

This study innovatively constructed a comprehensive and coherent journey map for family caregivers of patients with intracranial tumors through the systematic synthesis of qualitative evidence. Distinct from previous research that often focused on isolated stages or single dimensions[59], this map clearly demonstrates that caregiver experience constitutes an integrated trajectory profoundly intertwined with the medical progression of the disease, characterized by an inherent stage-wise regularity and dynamic evolution. The delineated stages—from the screening and diagnosis phase, perioperative period, continuation treatment phase, disease progression phase, and end-of-life care phase to the bereavement and reconstruction phase—are not merely a simple chronological sequence. Instead, they are demarcated based on critical transition points where the caregiver's core tasks, dominant emotions, and

support needs undergo fundamental shifts.Furthermore, the journey map reveals the strong dynamism and non-linear nature of this trajectory. The caregiver's experience does not represent a unidirectional, smooth transition but rather involves recurrences and overlappings of challenges and emotions. The construction of this journey map acknowledges the uniqueness of each stage, thereby providing targeted objectives for stage-specific, precise support interventions. Simultaneously, it emphasizes the interconnectedness and evolution between stages, suggesting that the support system should possess sufficient flexibility and continuity to respond to the inherent uncertainties in the caregiver's journey.This journey map transforms fragmented qualitative insights into an orderly navigational chart. It enables healthcare professionals, policymakers, and caregivers themselves to shift from a mode of reactive coping to one of proactive planning, representing a crucial step towards establishing a caregiver-centered support system.Moreover, this study transcends limitations related to specific age groups or caregiver roles. Compared to the research by Rolfe et al. (2025) [60], which focused on a narrower caregiver demographic (e.g., parents), the present study encompasses a broader range of caregivers, including those in various family and social roles. This broader scope allows for a more comprehensive reflection of both the commonalities and differences in caregiver experiences across different disease stages, patient ages, family structures, and cultural backgrounds, thereby advancing the development of personalized, whole-cycle care systems.

Journey Map-Oriented Nursing Practice: The Role Positioning and Support Pathways of Nurses in Whole-Course Care

Based on the constructed intracranial tumor caregiver journey map, this study identifies key support opportunities at each stage, which provide clear intervention directions for nursing practice. As core members of the care team, nurses play a pivotal role throughout the caregiver's journey. They must fulfill diverse and continuous professional responsibilities tailored to the characteristics and needs of different stages, thereby facilitating a paradigm shift from reactive response to proactive support.

During the screening and diagnosis phase, caregivers face information overload and emotional shock. The core responsibility of nurses at this stage is to provide emotional support and serve as an information bridge for caregivers. A specialized nurse coordinator, who possesses extensive experience in oncology nursing and has received targeted communication skills training, should establish a trusting relationship with the caregivers of patients with intracranial tumors[61]. This coordinator would undertake key communication tasks, assess caregiver needs and coping strategies, and provide emotional support. A three-arm randomized controlled trial (RCT) led by Boele et al. [62] demonstrated that a nurse-led emotional support model significantly alleviates psychological distress in these caregivers. Simultaneously, acting as a bidirectional communication bridge, the coordinator can accurately and timely convey the concerns and demands of patients and their families to the healthcare team. This ensures the holistic coordination of subsequent treatment and follow-up, maintaining synchronized information flow.

When caregivers enter the critical transitional perioperative period, it signifies that they begin undertaking specific and demanding caregiving tasks. At this stage, the core responsibility of nurses is to act as educators and enablers, providing essential surgical knowledge and skill support, guiding caregivers to effectively fulfill their roles, and thereby enabling their more active participation in the rehabilitation process. Nurses should offer structured perioperative education to caregivers, covering key topics such as surgical procedures, preoperative skin preparation, postoperative wound care, pain management, and complication recognition[63]. Through systematic training, this approach tangibly enhances caregivers' caregiving competency and confidence, which can effectively reduce patient hospital stays and minimize complication rates, consequently alleviating the caregiving burden.

Upon entering the continuation treatment phase, caregiving work becomes increasingly routinized yet highly complex. In this stage, the nurse's role expands to that of a long-term manager and support coordinator. On one hand, nurses can provide educational programs for caregivers of patients with intracranial tumors, covering topics such as managing disease-specific symptoms (e.g., tumor-related epilepsy) and strategies for addressing cognitive changes[64]. On the other hand, nurses can proactively assume the role of coordinator for the caregiver support network. This involves assisting in organizing peer support activities for caregivers[65], facilitating experience sharing and emotional mutual aid to alleviate their sense of isolation.Simultaneously, nurses should integrate the caregiver's own health status into routine assessment and intervention protocols. By utilizing approaches such as psychoeducation, mindfulness-based interventions, and cognitive-behavioral therapy-based strategies to enhance caregiver resilience[66], they can systematically safeguard the overall well-being of caregivers, thereby effectively preventing the deterioration of their physical and mental health.

When the patient's condition enters the disease progression phase, its core feature is the definitive deterioration of the disease state. As a transition between continuation treatment and palliative care, caregivers often face a heavy care burden and decisional dilemmas due to a lack of understanding and psychological preparedness for the trajectory of disease worsening[67]. In this stage, the nurse's role further expands and deepens. Building upon enhancing caregiver resilience, the nurse also acts as a facilitator for Advance Care Planning (ACP) and decisional support. This involves assisting patients, families, and the healthcare team in communicating about treatment goals and the impending transition to an end-of-life state, thereby promoting the discussion and implementation of hospice and palliative care plans[68].

During the end-of-life care phase, due to impaired decision-making capacity resulting from neurocognitive deficits, the goal of terminal care shifts to enhancing the quality of a dignified death for the patient. The key lies in improving caregivers' satisfaction with the care process and avoiding unnecessary transitions in the care setting, thereby ensuring the continuity and stability of hospice and palliative care[69]. In this phase, the core role of nurses transforms into that of practitioners of comfort care and providers of humane support. A crucial responsibility is to actively collaborate with caregivers to clarify care goals and treatment preferences based on the values held by both the patient with an intracranial tumor and their caregiver, in order to develop a personalized hospice care plan[70]. Furthermore, assisting families in implementing Advance Care Planning (ACP) programs during the end-of-life phase[71] helps deliver targeted nursing care aligned with caregivers' needs, thereby reducing hospitalization rates and avoiding unnecessary aggressive interventions at the end of life.

Finally, in the bereavement and reconstruction phase, the nurse's role transforms into that of a grief companion and facilitator of social reintegration. Nursing support does not terminate with the patient's death. Nurses can conduct ongoing follow-ups through various means such as phone calls and letters[72]to

assess the bereaved individual's grief response. They can utilize self-report tools for standardized risk screening to identify caregivers experiencing prolonged or complicated grief disorder[73], providing initial grief counseling or referring them to professional psychological services or support groups[74]. Furthermore, nurses can offer telehealth support services to provide information and guidance on life reconstruction for caregivers of patients with intracranial tumors[75]. They can encourage the gradual resumption of social activities, the rebuilding of social networks, and the search for new life meaning and identity[76], thereby facilitating a smooth transition out of the caregiver role.

The caregiving journey for individuals with intracranial tumors is fraught with challenges and is inherently dynamic. Nurses should establish a core philosophy of whole-course management in their practice. Guided by the journey map, they must flexibly assume multiple roles across different stages—such as educator, coordinator, manager, advocate, carer, and companion. By providing continuous, proactive, professional, and humanistic support, nurses can effectively empower caregivers and help construct a family-centered, integrated care support system throughout the entire trajectory. This is not only crucial for enhancing caregiver well-being but also represents a vital component in achieving high-quality, comprehensive management of intracranial tumors.

Building a Dynamic and Precision Support System: A Clinical Intervention Framework and Practical Translation Based on the Journey Map

The journey map constructed in this study goes beyond systematically identifying the burdens and challenges faced by caregivers throughout the entire trajectory[77]; it also represents a paradigm shift from problem description to framework construction. By employing the journey map as a structural framework, it integrates key junctures in neuro-oncological diagnosis and treatment. The core principles are whole-course coverage, precision intervention, and dynamic adjustment.At stages including the screening and diagnosis phase, perioperative period, continuation treatment phase, disease progression phase, and bereavement and reconstruction phase, standardized tools should be used to proactively assess caregivers' level of information comprehension and social support status[78], implementing a model of proactive and preventive care rather than reactive care. By measuring the supportive care needs of caregivers for patients with intracranial tumors at each stage of the journey[79,80], telehealth platforms[81] can be leveraged to precisely deliver personalized information and skill guidance, ensuring the accessibility of specialized services.Furthermore, integrating caregiver mental health—a significant public health concern—into the clinical care pathway is a crucial step[82]. This involves conducting psychological screening at different stages[83] to assess the degree of caregiver psychological distress[84], and establishing a stepped-care intervention model. This model ranges from mental health education and structured peer support groups to providing professional psychological counseling for caregivers experiencing severe distress.Actively promoting a multidisciplinary service and care model that includes clinicians, neuro-oncology specialist nurses, psychologists, general practitioners, and others[85] is essential. Establishing electronic health records for patients and their caregivers to document their personalized needs, actively linking medical, community, and charitable resources, and formulating individualized support plans are recommended. These measures ensure information continuity and care coordination across different healthcare institutions and community services, providing caregivers with a sustainable mechanism of support.

Based on the integrated support framework derived from the journey map, previously fragmented and reactive services are reconfigured into a proactive, dynamic, and multidimensional continuum of support. This enables intervention measures not only to be precisely targeted at specific stages of the caregiver's journey but also to achieve macro-level dynamic calibration. Consequently, it offers a valuable reference for implementing a family-centered care model in clinical practice.

5.4 Directions for Healthcare Policy and Educational System Reform

The caregiver journey map constructed in this study and the core challenges it reveals go beyond a mere description of phenomena; they also provide a reference point for reforming healthcare service systems and educational directions. While undertaking arduous caregiving tasks, the health and well-being needs of caregivers for patients with intracranial tumors often lack systematic attention and support within the healthcare system. Therefore, targeted reforms at the policy and educational levels are urgently needed.For diseases such as intracranial tumors, characterized by a long course, prominent neuropsychiatric symptoms, and complex decision-making, caregivers are not only assistants in daily living but also crucial participants in medical decisions and close observers of symptoms. Consequently, at the healthcare policy level, it is necessary to promote a shift from a patient-centered care model[86] towards a care model that encompasses caregivers[87]. Health systems should actively foster a diversified research funding landscape involving governments, markets, international organizations, and civil society institutions, providing financial support, expanding insurance coverage, or establishing special funds for assistance[88]. This would alleviate the economic burden on families and ensure the sustainability of support services.Simultaneously, efforts should be made to establish cross-sectoral collaborative networks that integrate resources from healthcare, rehabilitation, social security, civil affairs, and community organizations. This would provide "one-stop" services for families affected by intracranial tumors, with care coordinators responsible for service linkage and needs follow-up.At the educational level, governments need to allocate dedicated funding and incentives to incorporate knowledge and skills for identifying and supporting caregivers into the core curriculum and continuing professional development for healthcare professionals. This includes strengthening training on family care for chronic critical illnesses, effective communication with caregivers, and cultivating awareness and competence among future healthcare professionals to adopt a care model inclusive of caregivers. The goal is to fundamentally recognize caregivers as indispensable partners within the healthcare team.

In summary, translating the insights from the journey map into tangible action necessitates a move in clinical practice towards greater refinement and pathway development. More critically, it requires a systemic and supportive restructuring of both policy and educational systems. Through this dual-track advancement—integrating clinical and policy initiatives—we can work to change the predicament faced by caregivers of patients with intracranial tumors and build a healthcare and social care system capable of providing sustainable support and enhancing their resilience.

Limitations of this study

This study has several limitations. First, the literature search was confined to English-language databases and did not include studies published in other languages. This may introduce language and cultural bias, potentially limiting the cross-cultural applicability and generalizability of the journey map's conclusions. Second, the integrated qualitative evidence inherently possesses subjectivity. Although a systematic thematic synthesis approach and multi-

researcher verification were employed, the interpretation of data and the distillation of themes may still be influenced by the researchers' standpoints and interpretive perspectives.Third, intracranial tumors are highly heterogeneous in terms of pathological type, malignancy grade, rate of disease progression, and patterns of neurological impairment. The journey map constructed in this study does not fully account for this internal heterogeneity. The included studies predominantly focused on malignant tumors, and different tumor types may lead to significant variations in caregiver experiences. Therefore, the applicability of the current map to specific intracranial tumor populations requires further validation.Fourth, there is a degree of bias in the caregiver sample structure across the included studies. Most studies predominantly involved spousal caregivers, with other perspectives being relatively underrepresented. This may result in an incomplete coverage of caregiving experiences across different family roles and social relationships.Fifth, the majority of the original studies employed a cross-sectional design, lacking longitudinal follow-up of the same caregiver cohort over time. Consequently, the stage delineation and dynamic evolution pathways within the journey map are primarily derived from the synthesis of cross-sectional evidence. The temporal continuity and authenticity of this trajectory need to be confirmed by future longitudinal studies.Finally, this study is currently at the stage of theoretical framework construction. The proposed journey map has not yet been empirically applied or its effectiveness evaluated in clinical settings. Its feasibility as a nursing practice tool, its effectiveness, and its actual impact on improving caregiver outcomes require verification through subsequent interventional research.

Conclusion

This study, through the systematic synthesis of existing qualitative evidence, constructed a six-stage journey map for caregivers of patients with intracranial tumors. It systematically reveals the core tasks, emotional trajectories, key challenges, and support opportunities throughout the entire process from diagnosis to bereavement. This map not only provides a holistic and dynamic framework for understanding caregiver experiences but also offers an empirical foundation for clinically implementing stage-specific supportive needs assessments and multidisciplinary collaboration, delivering targeted support interventions, and optimizing continuous care services. Simultaneously, it provides insights for policymaking, the development of medical professional education, and future research. Future work is needed to validate and adapt this map across diverse cultural contexts, to develop and evaluate corresponding interventions based on it, and to promote the establishment of a care model that fully integrates caregivers. The ultimate goal is to enhance the overall quality of care and the well-being of both patients with intracranial tumors and their families.

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Figures

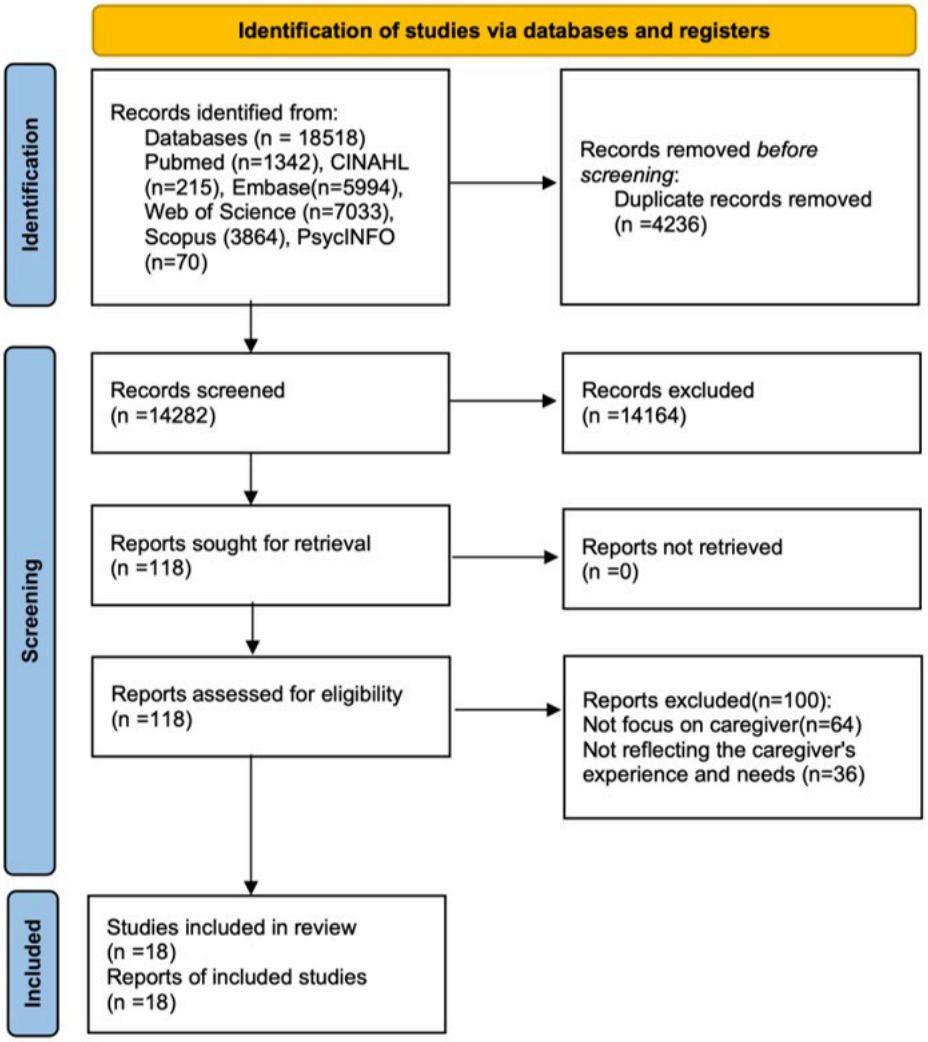


Figure 1

PRISMA flow diagram

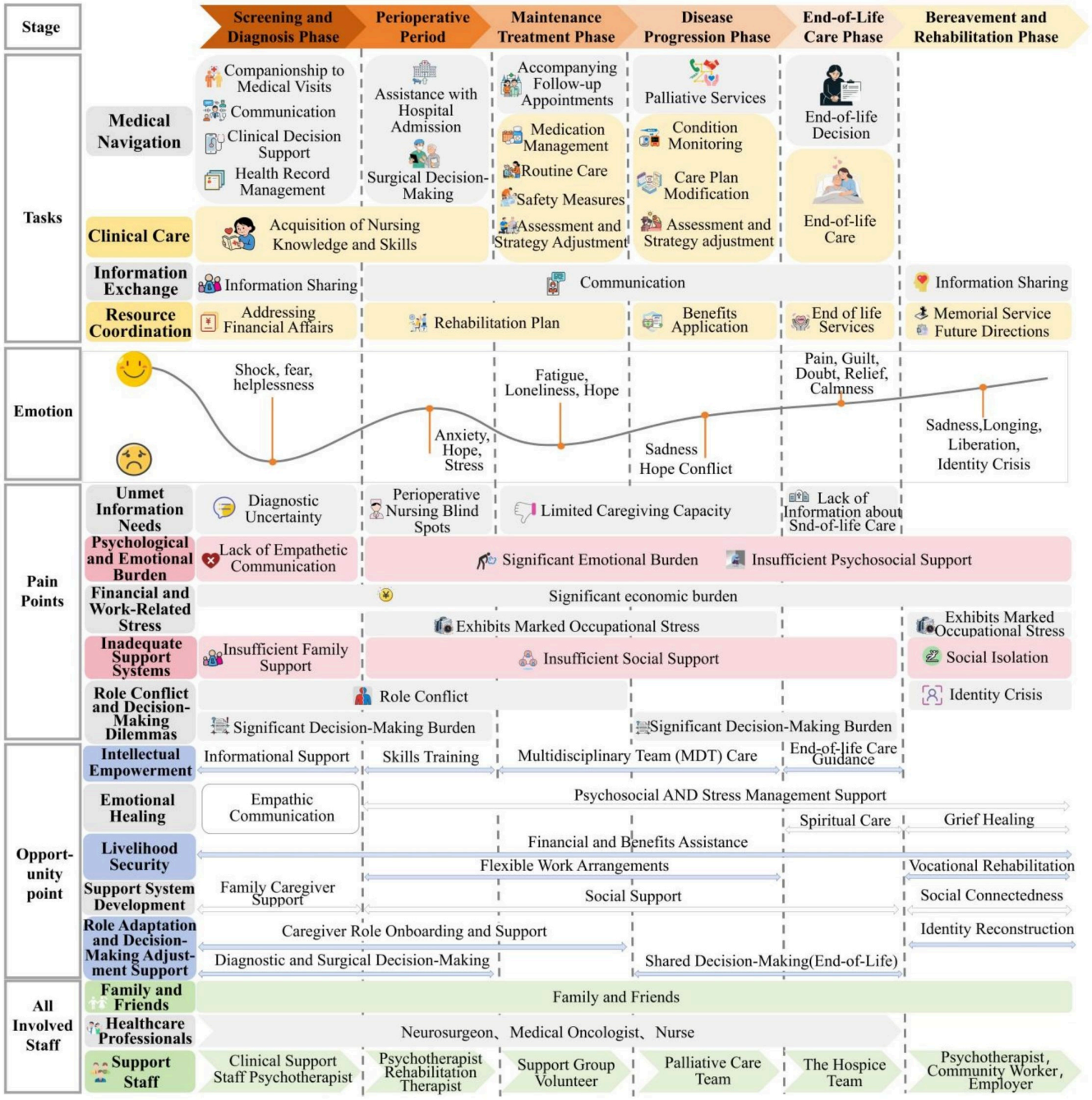


Figure 2

Intracranial Tumor Caregiver Journey Map.

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