

Review Article

Quality of Life in Caregivers of Patients with Brain Tumours: A Systematic Review and Thematic Analysis

James Tallant ^{1,2}, Lillie Pakzad-Shahabi ^{2,3,4}, Sylvie D. Lambert ^{5,6},
Matthew Williams ^{2,3,4} and Mary Wells ^{2,7}

¹*Surgery and Cancer, Imperial College Healthcare NHS Trust, London, UK*

²*Faculty of Medicine, Department of Surgery and Cancer, Imperial College London, London, UK*

³*Computational Oncology Group, Institute of Global Health Innovation, Imperial College London, London, UK*

⁴*Radiotherapy Department, Charing Cross Hospital, Imperial College Healthcare NHS Trust, London, UK*

⁵*St. Mary's Research Centre, Montreal, Canada*

⁶*Ingram School of Nursing, McGill University, Montreal, Canada*

⁷*Nursing Directorate, Imperial College Healthcare NHS Trust, London, UK*

Correspondence should be addressed to James Tallant; james.tallant@nhs.net

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Objective. (1) Examine QoL of caregivers of patients with brain tumours compared to population norms and other cancer caregiver groups, (2) appraise the content of quantitative QoL outcome measures utilised, and (3) assess to what extent QoL measures used in research align with caregivers' priorities. **Methods.** Systematic literature search of studies including caregivers of brain tumour patients using self-completed assessments of QoL. Extracted data from included studies included quantitative QoL outcome data, QoL outcome measures utilised, and the included QoL domains. The impact of brain tumour patient caregiving was assessed by summarising included data comparing brain tumour caregivers to other cancer caregivers and normative population data. QoL measures utilised by the studies and their domains were extracted, coded, and analysed by themes. The rates of investigation by theme were then compared to existing data on caregiver-own preference in relation to QoL. **Results.** 49 studies, including 57 outcome measures, incorporating a combined 124 QoL domains. Brain tumour caregivers reported lower QoL outcomes than population norms but similar to other cancer caregiver groups. Thematic analysis of QoL domains generated 7 themes: caregiving burden and adaptation, existential and self, family and social support, finances, information needs, physical symptoms and functioning, and psychological symptoms and wellbeing. The most investigated themes were physical and psychological symptoms, the most important for caregivers themselves were family and social support. **Conclusions.** Caregiving for brain tumour patients is shown to negatively affect QoL, particularly mental health, burden, and social life. Existing QoL research in caregivers of brain tumour patients predominantly utilises generic QoL measures designed for use in patients and draws a medicalised view of QoL priorities. The few studies using caregiver-specific QoL measures demonstrated closer alignment to caregiver preferences such as family and social support.

1. Introduction

Informal caregivers—the unpaid family and friends who form the mainstay of patient care and support at home—are known to experience significant negative impacts on their own physical health and psychosocial wellbeing, resulting in increased morbidity, anxiety and depression, marital strain,

and the restriction of the carer's own activities which can all contribute to negative perceptions of quality of life (QoL) [1–4]. Positive aspects of caregiving are commonly associated with a previously good relationship with the patient, a perception of caring tasks being less burdensome and the presence of effective formal and informal supportive networks to facilitate carers' own coping strategies [5–7].

Caregivers of patients with brain tumours are recognised as facing particularly rapid changes in roles and responsibilities with a potentially high burden and consequences for their lifestyle and QoL compared to caregivers of other cancer types [3, 8, 9]. This burden is felt alongside the expectation of significant symptom progression and the prospect of poor prognosis and reduced life expectancy [3, 10].

Increasingly, studies are using QoL and caregiver burden measures to quantify the impact of caregiving. However, a systematic review of QoL measures used with cancer caregivers concluded that few of these had been psychometrically evaluated and that responsiveness was low to caregivers' changing lifestyles and pressures [11]. Arguably, standardised, quantitative QoL outcome measures are an inherently poor assessment method for the highly individual concept of true QoL. However, given their quick and repeatable nature they form a cornerstone of experimental research, guiding the development and implication of services and interventions [12]. This review focuses on quantitative outcome measures due to this importance to the service development cycle, whilst attempting a novel method of comparing the domains deemed important by these outcome measures to those freely expressed by caregivers themselves.

This systematic review aims to assess the literature examining QoL among caregivers of patients with a brain tumour, including (1) comparing the QoL of caregivers of patients with brain tumour with population norms and QoL of other cancer caregiver populations, (2) appraise the content of self-administered QoL quantitative measures utilised, and (3) assess to what extent these QoL measures used in brain tumour caregiver research align with the priorities of cancer caregivers.

2. Methods

Review reporting is in line with updated PRISMA guidelines for systematic reviews [13]. Details of the protocol for this review were registered on PROSPERO (ID: CRD42020166356 [14]).

2.1. Search Strategy. Systematic searches of MEDLINE, Embase, PsychInfo, CINAHL, and Scopus as well as hand searches of citation lists were conducted in May 2021 and updated in December 2022 to find studies that included caregivers of patients with brain tumours. Key terms included those for “caregivers” and “brain tumours” (see Supplementary Data 1 for full list of search terms). Following multiple test searches, terms for QoL were not included in the final search strategy as these were deemed to restrict search results. Instead, terms relating to “quality of life” including specific domains such as “burden,” “psychological health,” and “physical health” were selected for by hand during title and abstract screening. This facilitated the inclusion of studies utilising related outcome measures within a looser description of QoL.

2.2. Eligibility Criteria

2.2.1. Inclusion Criteria

- (i) Studies including quantitative outcome data on the QoL of adult caregivers of adult patients (18 years and over) with a primary brain tumour. Studies with mixed caregiver/patient samples were eligible, as long as the data from caregivers of patients with brain tumours could be separately extracted.
- (ii) All types of quantitative designs were eligible, including observational and intervention studies (experimental or quasiexperimental).
- (iii) Outcome measures had to be completed by the caregiver only (only self-administered measures included, this excludes proxy outcomes).
- (iv) Data can be from self-administered outcome measures designed to capture overall QoL as well as domain-specific measures assessing aspects of QoL such as anxiety, burden, or strain.
- (v) All types of primary brain tumour (not metastatic disease) were included; no restrictions on patient diagnosis, period of treatment, or time since diagnosis.

2.2.2. Exclusion Criteria

- (i) Qualitative studies, editorials, commentaries, review articles, conference abstracts, or case studies
- (ii) Non-English language publications
- (iii) Studies of formal (professional) caregivers
- (iv) Caregivers of paediatric patients (or where disease was diagnosed in childhood (under 18 years))
- (v) Studies of caregivers of patients with metastatic brain disease (there is a high likelihood that patient symptoms and care needs impacting on caregiver QoL will be driven by extracranial disease).

2.3. Study Selection. All retrieved study references were downloaded to Mendeley [15] with duplicates subsequently removed. The references were transferred to Covidence [16] for separate title and abstract and then full-text screening against eligibility criteria. Screening was conducted independently by two researchers (JT and LP-S) with conflicts resolved through discussion, and inter-rater reliability was not formally tested.

2.4. Data Extraction. The findings from the included studies were manually extracted and collated in an Excel document. Key study characteristics extracted included author, publication year, study design, primary and secondary aims of study, and caregiver demographics. The self-administered QoL measures used by the included studies and QoL outcome data were also extracted. Where applicable, data comparing study participants and normative or other

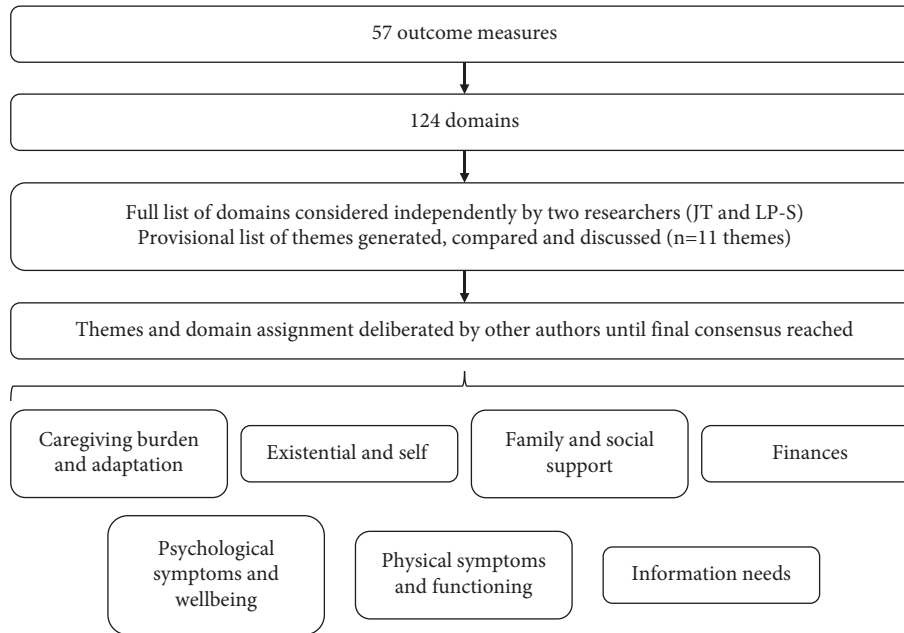


FIGURE 1: Representation of process for thematic analysis of included outcome measure domains.

caregiver data were collated to identify differences in QoL impact. Methodological quality and risk of bias assessments were completed for all comparative studies used to identify QoL impact, with reference to prior work on assessment tool selection [17].

A separate spreadsheet was constructed to record detailed data pertaining to the caregiver self-administered QoL measures used by the included studies. This included their frequency of use (number of included studies utilising the measure), the number of included items within each measure, and the domain names (taken either from the included study paper or where this was not available, the primary literature on the outcome measures' development). All QoL measures were categorised by the reviewers as either "comprehensive QoL" or "domain-specific" measures, both with subgroups for generic and caregiver-specific measures. Outcome measures were designated as "comprehensive QoL" if they included all domains of QoL (physical, emotional, and social health) [18]. Conversely, those measures assessing a subset of QoL domains, e.g., emotional health only, were labelled "domain-specific." "Generic" measures were those designed for use with the general population or a nonspecific patient group, "caregiver-specific" measures were those which were designed for use specifically with caregiver populations.

To explore the areas of life being assessed by the included studies, an inductive thematic analysis approach was used based on the principles set out by Braun and Clarke [19]; this was adapted so that the domains of QoL captured by all included outcome measures formed the codes from which initial themes were generated. This analysis was initially conducted by two of the authors (JT and LP-S) independently before being brought together for discussion and then agreed upon in collaboration with other authors. The assignment of domains to themes was again initially

conducted separately before being agreed upon by all authors, resulting in the final themes (Figure 1) with distinct definitions (Table 1).

Following the allocation of domains to themes, the next stage of analysis was to quantify the extent to which each theme was covered by the included outcome measures. This was initially conducted as a simple count of the domains assigned to each theme. Then, to reflect the extent to which each theme was assessed across all studies, a frequency-weighted count was performed. This weighted each domain by the number of included studies that utilised the outcome measure from which it originated (illustrative example in Figure 2). This analysis was first performed to include all domains, followed by subanalyses of domains originating from comprehensive QoL outcome measures only and then domain-specific outcome measures only. Spider plots were constructed within Excel to provide a visual representation of the distribution of domains across the themes.

To assess whether the included QoL domains aligned with caregivers' priorities, previously published data were used [20]. These data were chosen, as this study was the only one which used an individual index measure (in this case, Schedule for the Evaluation of Individual Quality of Life-Direct Weighting (SEIQOL-DW)) to ascertain the QoL priorities of a relatively large cohort of 205 cancer caregivers. The authors of the comparator data have coded these results into domains, providing the number of caregivers highlighting items within each domain. Here, the SEIQOL-DW domains are coded to the themes generated within this review and weighted as a percentage of caregivers raising each domain as a priority. These weightings are presented on the same spider plots as the thematic analysis results to give a visual representation of agreement between the themes investigated and those seen as most important to caregivers.

TABLE 1: List of themes and their descriptions alongside distribution of 111 included domain names.

Theme	Description	Number of domains assigned to theme
Caregiving burden and adaptation	The practical implications resulting from the lifestyle changes brought on by becoming a caregiver. Includes domains relating to increased burden and workload, changes to normal activities and coping strategies employed to manage these changes	20
Existential and self	The inner thoughts and reflections on current changes to lifestyle and future implications. Includes elements examining fears for the future, spirituality, and self-esteem	14
Family and social support	The informal support structures, both physical and emotional, available to caregivers from within their family and wider social network. Includes assessments of caregiver satisfaction with family and social support, family wellbeing and functioning, and assessments of domestic stability and opportunity	27
Finances	Assessments made of the financial impact of becoming a caregiver	5
Information needs	Assessments of the degree to which caregivers require, and are supplied with, information on varying aspects of their new role including knowledge on disease and treatment and gaining help and support	4
Physical symptoms and functioning	Assessments of the physical health impact of becoming a caregiver	24
Psychological symptoms and wellbeing	Assessments of all domains of psychological health within caregivers. Includes assessments of specific domains such as anxiety and depression as well as assessments of the impact of psychological disturbance on caregiving role	29

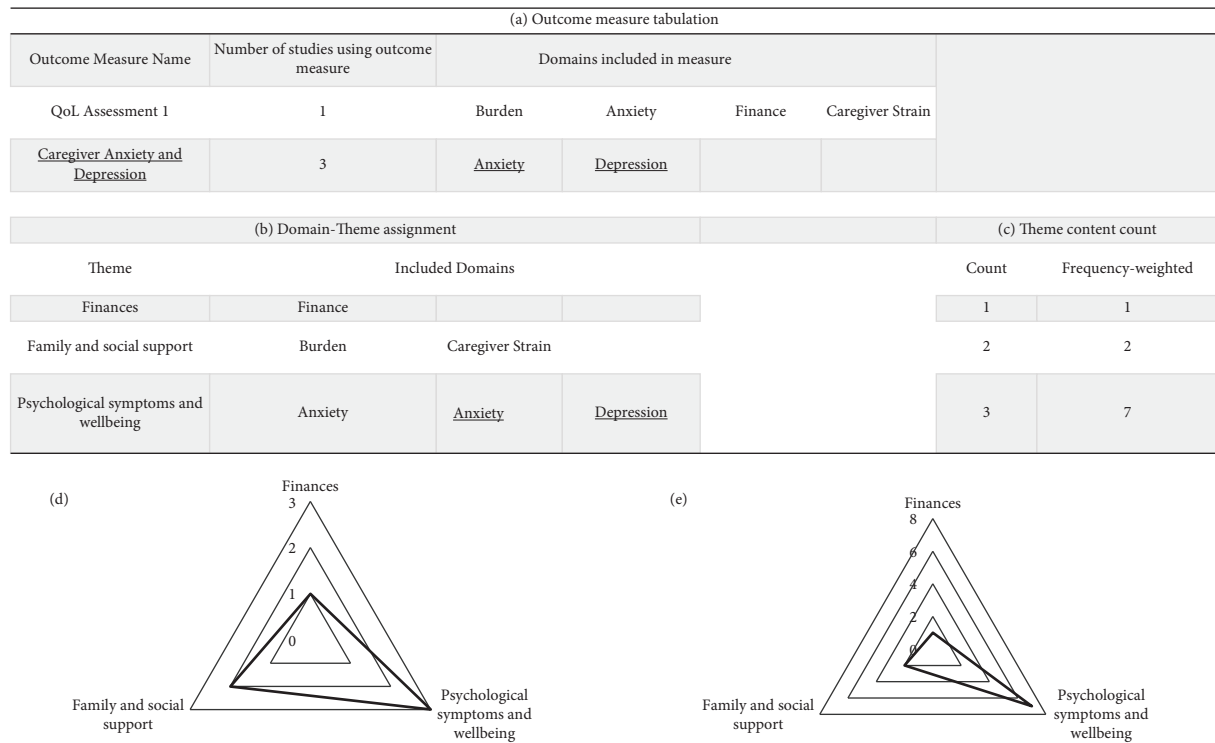


FIGURE 2: Illustration of domain-theme mapping tallies by simple- and frequency-weighting. (a) All included outcome measures are listed alongside the number of studies which utilise them and the domains which are covered within each measure. (b) All included domains are mapped to themes. (c) Simple count collates the number of domains within each theme; frequency-weighted count multiplies each included domain within a theme by the number of studies using the outcome measure from which it originated (in this example, anxiety and depression (underlined) are both counted as 3 due to the outcome measure they originate from (caregiver anxiety and depression) being used in 3 of the included studies). Totals are represented in spider plots of both the simple count (d) and frequency-weighted (e) tallies.

3. Results

3.1. Selection of Studies. The PRISMA flowchart is shown in Figure 3. Initially, 4,445 articles were identified. Of these, 4,289 were removed through title and abstract screening. 156 full-texts were assessed, and a further 115 articles were removed at this stage. This left 41 studies for inclusion in this review (study details summarised in Supplementary Data 2). Reasons for exclusion are listed in the PRISMA flow chart; the two leading reasons were study design (e.g., qualitative designs) and outcome measures (e.g., measures completed by caregivers as proxy patient outcomes). A further 8 studies were identified when the search was updated in December 2022 for a total of 49 included studies.

3.2. Study Design of Included Studies. Of the included studies, 13 were experimental (5 with participant randomisation) and 36 were observational trials. 29 studies reported cross-sectional data, and 20 reported longitudinal data. 11 studies reported comparisons to normative or other cancer caregiver populations.

3.3. Participants. In total, the studies included 3,514 caregivers completing at least one self-administered QoL measure (study range 20-268 participants, mean sample size = 71, median = 61). Most caregivers were female, and the spouse/partner of the patient, with an average reported

mean age of 52 years. Of the included studies, 26 recruited caregivers were of malignant brain tumours only (grade III and/or IV tumours), with the remaining 23 studies recruiting caregivers of both malignant and benign tumours.

3.4. QoL Impact for Caregivers of Brain Tumour Patients (Review Question 1). A comprehensive description of study results is included in Supplementary Data 3 and methodological quality assessments in Supplementary Data 4. Six studies [21–26] included normative datasets from the general population for comparison and showed mixed (positive and negative) results across their respective physical, psychological, and social domains. Five of these studies [21–23, 25, 26] utilised the generic QoL measures SF-12 or SF-36, and all demonstrated significantly lower (worse) scores for the mental health domains in the brain tumour caregiver group in comparison to the general population, with the physical component scores returning mixed results (Table 2). One comparative study (Janda et al.) used the FACT-GP measure, finding overall caregiver QoL scores to be clinically significantly lower than comparative data from the local population. All six studies also utilised a domain-specific measure of anxiety and/or depression for comparative analysis and found that brain tumour patient caregivers had significantly worse scores for anxiety and/or depression than the general population.

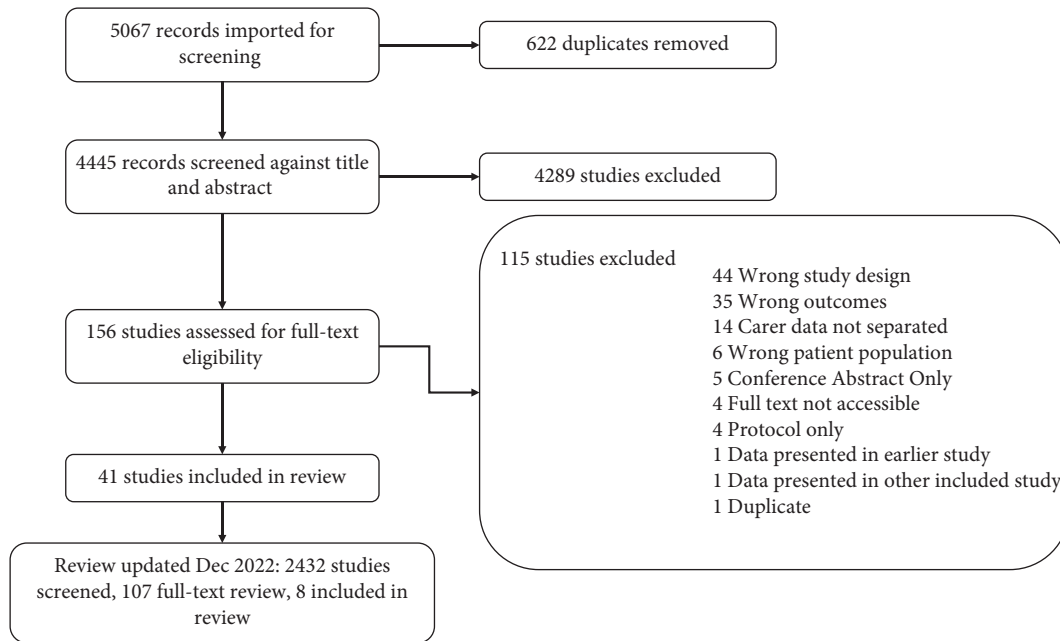


FIGURE 3: PRISMA flow diagram of study selection.

Seven studies [23, 27–32] compared their outcomes to other cancer caregiver populations. Four of these studies utilised comprehensive QoL outcome measures (SF-12, SF-36, CarGOQoL, or CQOLC) and returned mixed results. The SF-12 was used in one study [28], demonstrating a significantly lower mental component score at baseline in the brain tumour caregiver group. The SF-36 was used in two studies [23, 29], the only significant difference was seen in the mental component summary of one study [29] with lower (worse) scores recorded by the caregivers of high-grade gliomas compared to their comparator caregiver group (non-small cell lung cancer). The Caregiver Oncology Quality of Life (CarGOQoL) questionnaire was utilised by one study [23] which demonstrated glioma caregivers experienced significantly lower scores for the domains of burden and leisure times than other cancer caregiver groups. The Caregiver Quality of Life-Cancer (CQOLC) questionnaire was used by one study [30] which demonstrated a statistically lower (worse) QoL result for brain tumour caregivers than other cancer caregiver populations.

Domain-specific outcome measures utilised in cancer comparison studies included Hospital Anxiety and Depression Scale (HADS), Family Appraisal of Caregiving Questionnaire (FACQ), Assistance with ADLs, Depressive symptoms Anxiety Stress Scale (DASS), Caregiver Strain Index, WHOQOL-BREF (psychological component only), and the brief social support questionnaire. Significant results were found for FACQ: higher strain for the brain tumour group 3.35 (0.86) vs. other cancer 2.85 (0.72) $p = 0.019$ [28], assistance with ADLs: higher workload for the brain tumour group 2.35 (1.06) vs. other cancer 1.66 (0.72) $p = 0.039$ [28], DASS: higher depression scores in other cancer group than the brain tumour group (9.19 (8.58) vs. 4.93 (4.4), $p = 0.21$) [31], WHOQOL-BREF: worse scores for other cancer group

compared to the brain tumour group (20.35 (4.30) vs. 22.67 (2.66), $p < 0.05$) [32].

3.5. QoL Outcome Measures Utilised (Review Question 2). The included studies collectively utilised 57 different self-administered QoL measures (summarised in Supplementary Data 5). Of these measures, 10 were categorised as comprehensive QoL (8 generic measures, 2 cancer caregiver-specific QoL measures) and were used in almost half of the studies. The most frequently used comprehensive QoL outcome measure was the SF-36 used in 10 studies. The remaining 47 outcome measures were categorised as domain-specific measures (35 generic, 12 caregiver-specific). Nearly all studies utilised at least one domain-specific measure (range 1–5 domain-specific measures per study; mean = 2.1, median = 2). The most frequently used domain-specific outcome measure was the Hospital Anxiety and Depression Scale (HADS), which was used in 14 studies.

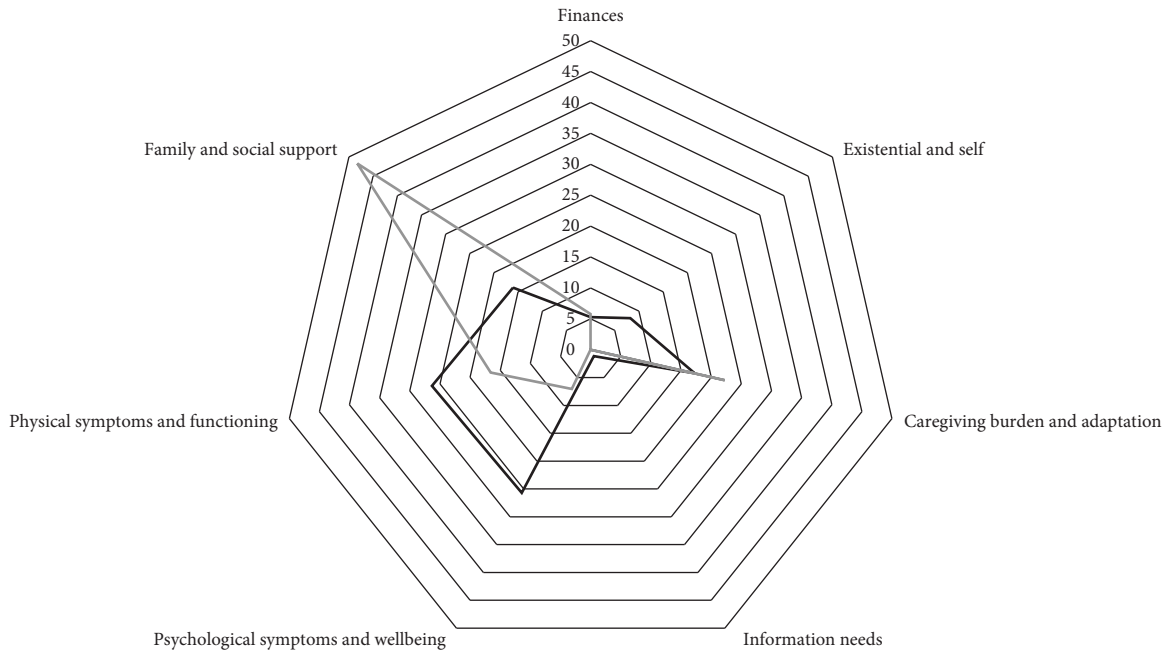
3.6. Thematic Analysis of QoL Domains (Review Questions 2 and 3). Five of the reported 57 outcome measures did not include any named domains and so could not be included in the thematic analysis: Carer Support Needs Assessment Tool (CSNAT), Fox Simple Quality of Life Scale, the Numeric rating scale of QoL, Patient Generated Index, and SEIQoL-DW. The remaining 52 measures included 124 named domains which were taken forward to the thematic analysis (Figure 1), resulting in seven themes described in Table 2. The frequency-weighted distributions of domains to themes, alongside the caregiver-reported domains of the comparator data [20] are displayed in [20].

As can be seen in Figure 4(a), the domains from all 52 outcome measures (blue) demonstrate a noticeably different

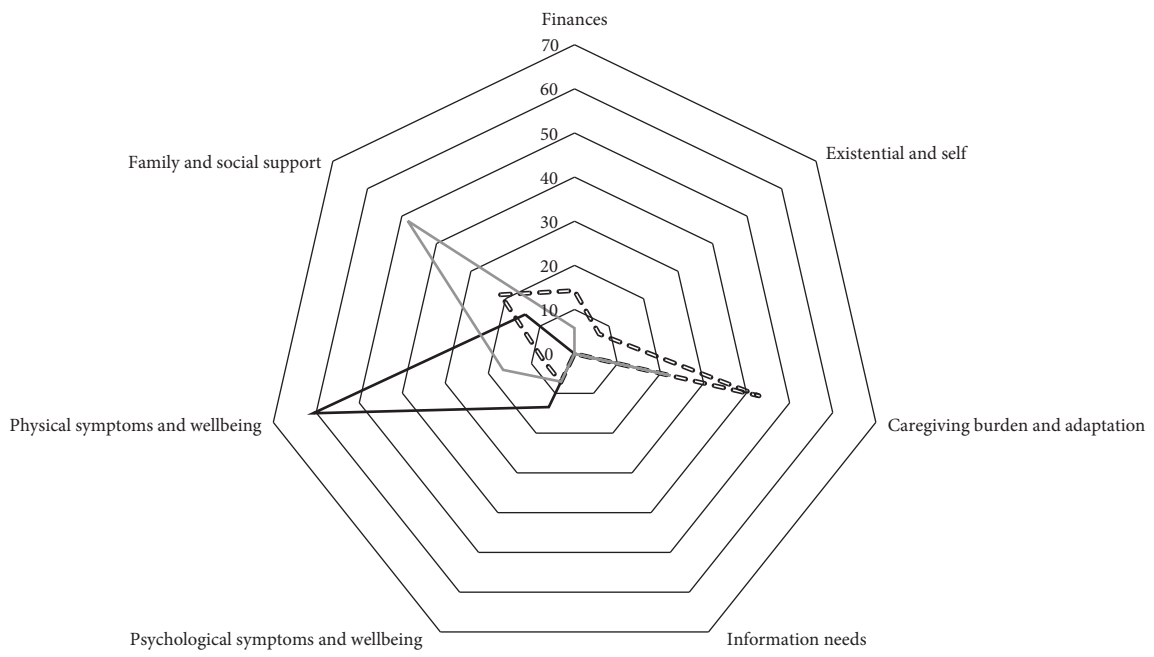
TABLE 2: Summary of outcome data from included comparative studies using the SF-36 and SF-12 QoL questionnaire with caregivers of brain tumour patients.

Outcome measure	Domain	Normative comparator means ⁺	[22] (n = 100) mean (SD)	[25] (n = 72) mean (SD)	[23] (n = 50) mean (SD)	[26] (n = 45) mean (SD)	[21] (n = 84) mean (SD)
SF-36	Physical functioning	84.46	92 (14.39)***	93.19 (10.08)***	80.65 (20.96)		
	Role physical	78.21	76.76 (33.19)	80.22 (33.29)	34.78 (39.61)***		
	Bodily pain	73.67	74.43 (25.06)	75.10 (22.87)	59.83 (23.86)**		
	General health	65.22	68.81 (17.29)*	69.53 (17.92)	62.28 (22.16)		
	Vitality	61.89	50.55 (19.9)***	54.31 (20.68)**	41.43 (21.48)***		
	Social functioning	77.43	58.66 (26.97)***	62.76 (26.02)***	59.69 (25.68)***		
SF-12	Role emotional	76.16	48.09 (36.79)***	47.88 (35.72)***	28.37 (33.32)***		
	Mental health	66.59	48.32 (21.56)***	50.72 (22.46)***	44.49 (18.89)***		
	Physical component summary	49.0				48.4 (9.1)	43.4 (5.1)***
	Mental component summary	52.2				42.9 (11.2)***	34.8 (9.2)***

Higher values represent better QoL; * = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$.



(a)



(b)

FIGURE 4: Continued.

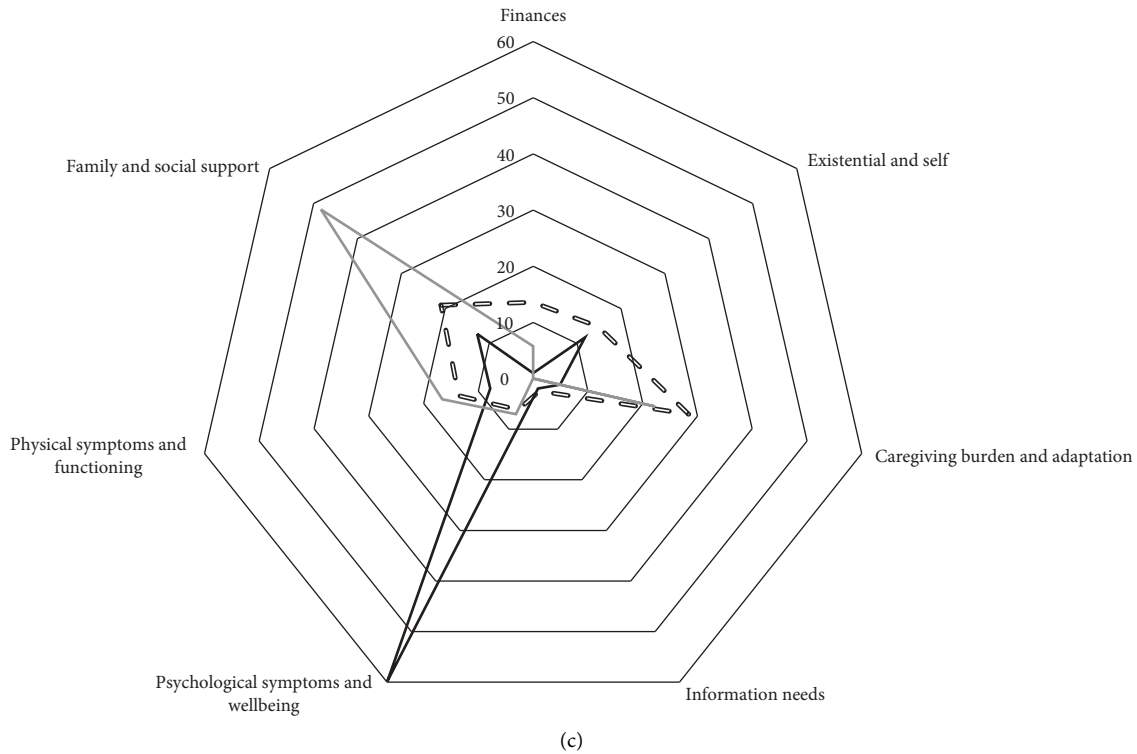


FIGURE 4: Representation of the frequency-weighted distribution of domains to themes (as percentage of domains included in each analysis) in comparison to the frequency of caregiver freely given QoL priorities. (a) All 111 included domains (black) compared to caregiver-reported priorities from Hamidou et al. [20] (grey). (b) Distribution of domains from comprehensive QoL outcome measures for both generic (black line) and caregiver-specific outcome measures (dotted line), alongside caregiver-reported priorities (grey). (c) Distribution of domains from domain-specific outcome measures for both generic (black) and caregiver-specific outcome measures (dotted), alongside caregiver-reported priorities (grey).

distribution than the domains taken from the normative data set (grey); with an over representation of domains concerned with physical and psychological health compared with caregiver priorities of family and social support. Figure 4(b) highlights that most domains originating from generic comprehensive QoL measures were mapped to the theme of physical health and functioning. There were no domains in these measures which mapped to the themes of finances, existential and self, or information needs. In contrast, caregiver-specific QoL measure domains mapped most frequently to the themes of caregiving burden and adaptation and family and social support. There were no domains in caregiver-specific QoL outcome measures that mapped to the theme of information needs. Figure 4(c) shows that the majority of domains in generic domain-specific measures mapped to the theme of psychological symptoms and wellbeing; predominantly, these assessed anxiety and depression. The domain-specific outcome measures designed for caregivers mapped more evenly between the themes, with the highest proportion falling in the caregiving burden and adaptation theme, and information needs being the least mapped theme. In comparison to generic outcome measures, the caregiver-specific measures show a closer alignment with caregiver generated priorities, notably by their focus on caregiving burden and adaptation, the second most frequently raised theme in the comparator

data. These measures also demonstrated a consistent representation of domains covering family and social support, the theme most frequently prioritised by caregivers themselves.

4. Discussion

This systematic review summarizes the current body of quantitative research in QoL of caregivers of patients with a brain tumour. 49 studies, using 57 different self-administered outcome measures pertaining to QoL were included in the analysis. Only two of the included outcome measures (CQOLC [33] and CarGOQoL [34]), used by five of the included studies, were specifically designed to assess comprehensive QoL specifically in cancer caregiver populations.

We intended to collate and summarise the quantitative QoL impact on this caregiver group. However, the low consistency in both study design and outcome measure usage among studies, made cross-study comparisons challenging. Where possible, we compared data from caregivers of brain tumour patients with the general population or other cancer caregiver groups. Generally, outcomes from comprehensive QoL measures returned lower (worse) QoL outcomes compared to the general population, particularly for mental health domains, though in comparison to other

cancer caregivers the results were more equivocal. Outcomes from mental health, caregiver burden, and leisure time domains were some of the most consistently negatively impacted when compared to both normative and other cancer caregiver populations. These findings correspond with existing qualitative research [35, 36] into the burden and distress experienced by these caregivers related to the combination of psychological and physical symptoms of malignant brain tumour patients.

To generate an understanding of the areas of life most frequently assessed by the existing body of research and the outcome measures utilised within it, thematic analysis was undertaken and identified seven overarching themes. Mapping of all the measures' named domains identified a focus on caregivers' psychological and physical health, neglecting other important domains such as information needs, finances, and existential issues. Generic comprehensive QoL outcome measures tended to focus on physical symptoms and functioning; whilst generic domain-specific measures predominantly included psychological symptoms, notably anxiety and depression. In contrast, caregivers' own priorities were much more likely to cover topics such as family and caregiver burden; themes which were more consistently included in caregiver-specific outcome measures. This disparity supports the concern that generic comprehensive QoL measures—typically health-related QoL (HRQoL) questionnaires—which are designed to evaluate patient outcomes do not sufficiently capture the specific concerns of caregivers and may represent an overly restrictive, medicalised view of “quality of life” [7, 37, 38]. The tendency for caregiver-specific measures to prioritise issues related to family, relationships, and support networks is supported by qualitative evidence which highlighted that brain tumour caregivers were primarily concerned with developing connections with others and establishing effective support networks [39].

This review demonstrates that studies assessing QoL in caregivers of patients with brain tumours need to be more tailored to the needs and concerns of caregivers themselves, namely, access to support and relief of caregiver burden. QoL has typically been assessed by the completion of standardised questionnaires encompassing domains of life easily quantifiable in large cohorts. However, these domains may not be deemed relevant or important to the individual completing them whose own perspective of QoL may include more philosophical concepts such as happiness, social engagement, and socioeconomic status [7, 38]. Whilst the array of negative impacts of caregiving has been recognised for a long time, research in this area has often taken the pragmatic approach of utilising the same HRQoL measures as for patients. This effectively extends the identity of “patient” to their caregiver, and fails to engage with concepts including caregiving fulfilment, retaining control, maintaining relationships, and feeling supported, highlighted by qualitative work as being some of the more important self-generated concepts [37]. Into this void, there are an emerging number of validated QoL outcome measures designed specifically for use within caregiver populations,

aimed at capturing the physical, emotional, and social burdens of caregiving for different conditions with the aim of producing reliable and transferable quantitative data to guide service provision [37].

This review illustrated the importance of utilising caregiver-specific outcome measures and suggests that greater standardisation of outcome measures for this population would be helpful. One possibility is the development of a core outcome set for caregiver QoL, which would help to reduce outcome measurement heterogeneity, allowing for improved meta-analysis as well as increased relevance to participants and clinicians for real-world use [40, 41].

Our review also suggests that the increased use of self-generated indices of QoL such as the patient-generated index and SEIQoL-DW may improve the specificity and depth of our understanding of the impact of caregiving. Such measures produce both a numerical outcome for quantitative assessment and enable the individual to propose the areas of QoL most important to them, encouraging a deeper understanding of the experience of caregiving. As demonstrated in our findings, these methods are less frequently used in studies of caregivers of adult patients, further research into the feasibility and reliability of using methods like these in clinical and research settings would be beneficial.

5. Conclusions

Caregiving, especially for those diagnosed with brain tumours, is well known to have negative effects on an individual's mental and physical health as well as their social engagement and working lives. However, there remains little consensus about the most applicable methodology for assessing QoL in this population. This systematic review has set out the current body of evidence detailing QoL assessment for caregivers of adult brain tumour patients and has conducted innovative analyses of the QoL domains under investigation.

From the available data, general comparisons to normative and other cancer caregiver populations demonstrated that brain tumour caregivers have lower QoL scores, notably in domains concerning mental health, burden, and social life; and that there may be a correlation with patient diagnosis (i.e., more advanced stage) and worsening caregiver anxiety and depression.

Our thematic analysis of the included QoL domains has shown that the preference for utilising generic HRQoL measures concentrates research efforts to the “medical” aspects of QoL, at the expense of the family and social priorities most expressed by caregivers themselves. This difference is reduced by utilising caregiver-specific outcome measures, which include a more even distribution of domains mapped to themes, strengthening the argument for their routine use in future research. Further still, the development of a core outcome set for caregiver QoL would help in formalising outcomes across caregiver research and improve the potential for future meta-analyses.

Data Availability

Data sharing is not applicable to this article as no new data were created or analysed in this study.

Disclosure

The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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Supplementary Materials

Supplementary Data 1: full search strategies for Embase and Medline databases. Supplementary Data 2: details of all included studies including aims and study design. Supplementary Data 3: outcome measures used and quantitative outcomes from all included studies. Supplementary Data 4: quality assessments of included studies which compared data to other cancer caregivers or normative data. Supplementary Data 5: all included outcome measures, their frequency of use, and included QoL domains. (*Supplementary Materials*)

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