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Psychosocial wellbeing of brain cancer patients and support persons: a mapping review of study types over time

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Author contribution

All authors conceived the study design and methodology. Author 1 and 2 contributed to data acquisition and analysis. All authors contributed to the interpretation of study findings, read and approved the final version.

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Abstract

Introduction: This review examined the**:** (1) number of publications exploring psychosocial outcomes of adults with brain cancer and/or support persons between 1999 and 2019 and whether there has been a change in the type of research over time; and (2) proportion of intervention studies meeting Cochrane Effective Practice and Organisation of Care (EPOC) research design criteria.

Methods: Embase, The Cochrane Library, Medline and PsycINFO databases were electronically searched January 1999 to December 2019. Articles were examined against inclusion/exclusion criteria and coded into measurement, descriptive or intervention categories. Intervention studies were assessed against the EPOC design criteria.

Results: 220 eligible publications were identified. The number of total publications significantly increased by an average of 1 each year (95%CI = 0.7-1.3; $p < 0.001$). There was no significant change in the proportion of publications by study type across three time periods. Descriptive research represented the majority within each time period. Of the 17 intervention studies, only 7(41%) met EPOC design criteria.

Conclusions: Published literature on brain cancer psychosocial outcomes has increased significantly. However, descriptive research dominates research output. To increase high-level knowledge that can guide psychosocial care of people with brain cancer, there is a need to undertake methodologically rigorous intervention trials.

INTRODUCTION

Brain cancer is a diverse group of tumours that affect physical and cognitive ability and can have a devastating effect on psychosocial outcomes (Huang et al., 2017; Sterckx et al., 2013). In 2012, there were 256,000 new cases and 189,000 deaths attributable to brain and central nervous system cancers worldwide (Ferlay et al., 2015). Brain cancer costs more per person than any other cancer and the 5-year relative survival rate has not significantly improved in the past 30 years (Australian Institute of Health and Welfare, 2017). There is growing emphasis on improving psychosocial wellbeing of brain cancer patients and their support persons (SPs) given the uncertain, often poor prognosis and debilitating symptoms and side effects of the disease and treatment (Catt et al., 2008; Chambers et al., 2015).

The quality of life of people diagnosed with brain cancer can be impacted by a range of physical, cognitive or behavioural, psychological, social and practical challenges (Randazzo & Peters, 2016; Sterckx et al., 2013). Physical symptoms and side effects of brain cancer may include headaches, fatigue, dysphasia and mobility issues (Chang et al., 2005; Sterckx et al., 2013). Depending on the tumour size and location, patients may also experience a range of cognitive and behavioural challenges, including changes in personality and an inability to complete complex tasks or process information (Chang et al., 2005; Sterckx et al., 2013). Brain cancer is also associated with poor psychological outcomes that are often misdiagnosed or unrecognised, meaning patients may not receive the support they need (Huang et al., 2017; Jenkins et al., 2016). Studies have shown significantly higher fatigue, symptoms of depression, cognitive dysfunction and altered mood states for brain cancer patients compared to non-CNS cancers (Hartung et al., 2017; Klein et al., 2003; Laack et al., 2005). Social concern, including dealing with stigma of an invisible and often misunderstood disease and changes in relationships, are also common (Janda et al., 2006).

Informal support persons (SPs) are individuals identified by the patient as helping them cope with diagnosis and treatment through support and communication (H. S. Campbell et al.,

2009). SPs of people diagnosed with brain cancer often experience their own psychosocial challenges, with studies reporting SPs having similar levels of emotional distress as cancer patients (McConigley et al., 2010; Schubart et al., 2008) and poorer psychosocial outcomes than SPs of other cancer groups (Aoun et al., 2015; Heckel et al., 2018). Dealing with changes in relationships or family dynamics, fear of losing the one they love, increased responsibility with practical issues and uncertainty about their ability to care for the person with brain cancer may lead to feelings of inadequacy and overwhelm SPs (McConigley et al., 2010; Schmer et al., 2008; Schubart et al., 2008).

Previous systematic reviews have synthesised the literature in the previous decade (e.g.(Ford et al., 2012; Sterckx et al., 2013)). Others have focused on quality of assessment tools (Afseth et al., 2019), the impact of interventions for specific domains such as information needs (Diamond et al., 2014; Langbecker & Janda, 2015), or phases of care, such as palliative phase and the end of life (Byrne et al., 2019; Walbert & Khan, 2014). However, the volume, type and quality of psychosocial research output in brain cancer is yet to be explored. Such research should follow a natural scientific progression to inform interventions aimed at reducing psychosocial burden. This is an important gap for a number of reasons. First, poor prognosis and largely unchanged survival rates have resulted in a growing emphasis on improving the quality of life and psychosocial outcomes of those affected by brain cancer (Chambers et al., 2015; Dirven et al., 2016). Second, suboptimal psychosocial outcomes in brain cancer are associated with significant personal and societal costs (Ford et al., 2012; Huang et al., 2017; Pace et al., 2017; Philip et al., 2018; Sterckx et al., 2013). Third, interventions applied to other cancer patients may not achieve similar improvements, given the unique challenges that people with brain cancer and their support persons can face (Chambers et al., 2015). Fourth, understanding research output can help determine current gaps in research and prioritise the type of research needed to improve psychosocial outcomes of people affected by brain cancer.

Examination of publication output volume, type and methodological quality, particularly over time, can therefore be a useful method to assess research effort and progression in a field. As the first step, measurement research involves the development of psychometrically robust tools that enable reliable and valid assumptions to be made about the prevalence and nature of psychosocial concerns for the population of interest (N. C. Campbell et al., 2007; Rychetnik et al., 2002; Westfall et al., 2007). Descriptive research data highlight shortfalls and discrepancies of care in a population (N. C. Campbell et al., 2007; Thiese, 2014).

Intervention studies, informed by descriptive research, provide causal evidence about the effectiveness of strategies in improving outcomes of interest (Rychetnik et al., 2002; Thiese, 2014). Such examination in other fields of research has found a lack of intervention research comparative to descriptive research (Bailey et al., 2010; Bryant et al., 2016; Mansfield et al., 2016; Sanson-Fisher et al., 2018). Therefore, this review aimed to examine the: (1) number of publications exploring psychosocial outcomes of adults diagnosed with brain cancer and/or their SPs between 1999 and 2019 and whether there has been a change in the type of research undertaken in three time periods (1999-2005, 2006-2012 and 2013-2019); and (2) proportion of intervention studies, published between 1999 and 2019, meeting EPOC research design criteria.

METHODS

Search strategy

Embase, The Cochrane Library, Medline and PsycINFO databases were electronically searched from January 1999 to December 2019 using MeSH terms and keywords. The search terms were selected with assistance from a medical librarian (see acknowledgements). The search strategy (see supplementary material for full strategy) was restricted to human studies published in English. A manual search was undertaken on existing reviews and all eligible intervention studies.

Inclusion and exclusion criteria: This review includes literature from the year 1999. This was selected as a starting point as a guidance document for the care of people with malignant glioma was released in 1997 (Davies & Hopkins, 1997). The document was developed in the UK by a large multidisciplinary working party that included patients and SPs. It proposes ways to improve patient care; provides suggestions for future research in the area and includes a toolkit for assessing treatment centres against proposed standards (Davies & Hopkins, 1997). For ease of identifying trends over time, publications are divided by year into three time periods (1999-2005, 2006-2012 and 2013-2019). Psychosocial wellbeing was conceptualised as incorporating either or both clinically determined dysfunction, such as measures of depression, and broader approaches including physical, psychological, social and spiritual wellbeing / quality of life measures (Paul et al., 2013). Publications were included if they:

1) examined psychosocial outcomes as defined above;

2) examined these outcomes among adults (18 years or over) diagnosed with any primary brain cancer at any stage of the cancer care pathway, from diagnosis to end of life, and/or their informal SPs; and
3) included a homogenous sample of brain cancer patients; or reported outcomes separately for brain cancer patients.
Publications were excluded if they solely focused on medical or treatment needs rather than psychosocial wellbeing; were biochemistry or cell biology studies; were prognostication studies; were a conference abstract, book chapter, editorial, case study, review article, protocol paper or where full text was unavailable.

Data coding: Title and abstracts were screened against the above eligibility criteria by one author (LB), a random subsample (10%) was screened by a second author (AW). LB and AW then examined the full text of remaining publications against the inclusion/exclusion criteria. Included studies were coded into measurement, descriptive or intervention categories. Coding discrepancies were recorded and blindly reviewed by a third author prior to being resolved by discussion between the three authors. **Measurement studies** reported on psychometric properties or development of tools to assess psychosocial outcomes for people diagnosed with brain cancer and/or their SPs, as previously defined. **Descriptive studies** included qualitative studies reporting on patient/SPs perceptions of psychosocial outcomes as defined in the inclusion criteria; and/or quantitative studies that examined prevalence and/or correlates of psychosocial outcomes among people with brain cancer and their SPs. **Intervention studies** examined the effectiveness of interventions with a primary or secondary aim of improving psychosocial outcomes of brain cancer patients and/or their SPs.

Assessment of methodological quality

All intervention studies published between 1999 and 2019 were further assessed to determine if they met the minimal EPOC research design criteria ("Cochrane Effective Practice and Organisation of Care. What study designs should be included in an EPOC review? EPOC resources for review authors.," 2017) by two authors (LB, AW). Relevant study designs include: randomised trials, non-randomised trials, controlled before-after studies, interrupted time series studies ("Cochrane Effective Practice and Organisation of Care. What study designs should be included in an EPOC review? EPOC resources for review authors.," 2017). For those interventions that met EPOC design criteria, study data was extracted and included:

sample characteristics; inclusion and exclusion criteria; study design; intervention; outcome measures; and study findings.

Analysis

The Kappa statistic was used to assess the level of inter-rater agreement between the authors who assessed the eligibility of full text articles. Trends in linear proportions were assessed using the Cochran-Armitage trend test. Time was coded as 1, 2 or 3, representing 7-year increments, and assumed to have a linear effect. Coefficients from this model are interpreted as the absolute difference in proportions for each 7-year increment in time.

RESULTS

Search Results

After removal of duplicates, a total of 1623 publications were identified and assessed against the eligibility criteria. Between 1999 and 2019, a total of 220 studies met the criteria for inclusion and were included in the review. The inter-rater agreement of authors who assessed full text articles was almost perfect (Kappa = 0.99). Figure 1 is a PRISMA flow chart of the search.

[Figure 1 here]

Number of publications between 1999 and 2019

Figure 2 presents the number of studies assessing psychosocial outcomes among primary brain cancer patients and their SPs published each year between 1999 and 2019. The number of publications significantly increased by an average of 1 each year (95%CI = 0.7-1.3; $p < 0.001$).

[Figure 2 here]

Number of publications by study type across three time periods (1999-2005, 2006-2012 and 2013-2019)

Figure 3 presents the number of studies by type published across three time periods. The proportion of measurement studies was 5% (n = 1) for 1999-2005, 6% (n = 4) for 2006-2012 and 8% (n=9) for 2013-2019. The proportion of descriptive studies was 95% (n = 20) for

1999-2005, 87% (n = 61) for 2006-2012 and 83% (n=107) for 2013-2019. There were no intervention studies for the period 1999-2005, the proportion of intervention studies was 7% (n = 5) for 2006-2012 and 9% (n=12) for 2013-2019. A Cochran-Armitage trend test for linear proportion showed there was no statistically significant change over time in the proportions of publications that were classified as measurement (Z = 0.659, p = 0.510), descriptive (Z = 1.524, p = 0.127) or intervention (Z = 1.390, p = 0.165) study types.

(Figure 3 here)

Number of intervention studies meeting EPOC design criteria

Between 1999 and 2019, 17 intervention studies were identified. Only 7 (41%) met EPOC research design criteria ("Cochrane Effective Practice and Organisation of Care. What study designs should be included in an EPOC review? EPOC resources for review authors.," 2017). Five of the intervention studies meeting EPOC study design criteria were RCTs and 2 were NRCTs (see Table 1). Four of the interventions targeted patients only, two studies targeted both patients and SPs and one study targeted SPs (with proxy reported patient data). Almost all studies (n=6) recruited and assessed participants during the treatment phase, with interventions designed to be delivered during or after active treatment. Only one of the interventions was focusing on the end of life phase. The types of interventions were primarily psycho-educational or cognitive rehabilitation programs delivered face-to-face, with only one intervention delivered online.

[table 1 here]

DISCUSSION

This review examined the volume and type of research undertaken between 1999 and 2019 to determine gaps in research efforts, as well as the methodological quality of interventions to improve psychosocial outcomes of brain cancer patients and their SPs. The number of publications examining psychosocial outcomes of people with brain cancer and their SPs significantly increased over time, suggesting a growing interest in understanding the psychosocial impact of this low survival, high burden cancer. However, research efforts in this field do not demonstrate a clear scientific progression. Firstly, only a small proportion of studies published within the three time periods were measurement studies (5% in 1999-2005, 6% in 2006-2012 and 8% in 2013-2019). Measurement studies are critical for ensuring that tools used to assess psychosocial outcomes are both reliable and valid (Rychetnik et al., 2002;

Thiese, 2014). Psychometrically robust tools that cover the full range of psychosocial concerns that may be experienced by both patients and their SPs are required, given the potential for cancer adversely impact on both of these individuals (Aoun et al., 2015; N. C. Campbell et al., 2007; Carlson & Bultz, 2003). Assessing the psychosocial wellbeing of both patients and SPs can also help determine the potential reciprocal relationships between these concerns. Tools should also be validated in brain cancer, given the potentially unique needs of this patient group (Catt et al., 2008; Klein et al., 2003; Sterckx et al., 2013). Ideally, these tools should be able to be feasibly implemented across different phases of the cancer care pathway, from the time of diagnosis, through treatment, follow-up and/or end-of-life (Aoun et al., 2015; Carlson & Bultz, 2003; Catt et al., 2008). This can help establish how concerns faced by patients and their SPs may evolve over time (Aoun et al., 2015; Carlson & Bultz, 2003).

Secondly, while the vast majority of research was descriptive in nature, an increase in the proportion of intervention research over time was not observed. Descriptive research in the field of brain cancer is important for obtaining relevant data on the prevalence and potential correlates of psychosocial burden. These studies provide correlational data on psychosocial outcomes and can make an important contribution to the identification of potential gaps in current psychosocial cancer care (Thiese, 2014). However, for the field to progress and for burden and gaps to improve, research needs to move beyond descriptive, correlational data and begin to test this data using causal science in order to alleviate psychosocial burden (Bryant et al., 2016).

Of the 17 intervention studies identified, only seven (41%) met EPOC design criteria ("Cochrane Effective Practice and Organisation of Care. What study designs should be included in an EPOC review? EPOC resources for review authors.," 2017). The failure to use appropriately rigorous research design by many of the existing intervention studies limits the potential contribution of this research to Level I Evidence and causal data (Bryant et al., 2016; Thiese, 2014). Most of the interventions that did not meet EPOC design criteria were uncontrolled before-after studies("Cochrane Effective Practice and Organisation of Care. What study designs should be included in an EPOC review? EPOC resources for review authors.," 2017). Of the seven studies that did meet EPOC design criteria, four trials focused on improving ‘quality of life’(Boele et al., 2013; Boele et al., 2018; Locke et al., 2008) and four trials focused on improving depression (Boele et al., 2018; Khan et al., 2014;

Ownsworth et al., 2015; Xiao et al., 2018). Four trials included patients(Boele et al., 2018; El-Jawahri et al., 2010; Khan et al., 2014; Ownsworth et al., 2015), one included SPs(Boele et al., 2013) while two trials included both patients and SPs as a dyad (Locke et al., 2008; Xiao et al., 2018). A more rigorous approach is necessary to inform optimal psychosocial brain cancer care.

Despite the potential for high psychosocial burden, research efforts in the field are limited, these findings suggest a need for further methodologically rigorous intervention. Further, these interventions should take into account the dyadic relationship of patient and SP and the unique impact of each diagnoses as brain cancer encompasses a range of different experiences (Chambers et al., 2015; Schmer et al., 2008). The large body of descriptive research presented in this review should provide a starting point for future intervention research which should be designed with careful consideration for previous findings. Development of interventions may also be led by successes in strategies to improve psychosocial wellbeing identified for other cancer types and other patient groups such as stroke, brain injury or dementia.

Implications for research and practice

To improve the psychosocial outcomes of this vulnerable population, the following steps are required. First, efforts to measure psychosocial outcomes of brain cancer populations should meet minimum psychometric methodological criteria (Paul et al., 2013). An optimal measurement tool should provide sufficient face validity, be easily understood, be of an acceptable length to complete, be sensitive to differences between individuals as well as within individuals over time and be reliable with minimal random error (N. C. Campbell et al., 2007; Rychetnik et al., 2002). Supporting the conclusions of recent reviews, our findings suggest tools with these qualities are currently lacking in neuro-oncology (Afseth et al., 2019). Robust tools are critical for ensuring accuracy of assumptions about the prevalence, severity and interactions of outcomes identified in descriptive research; and in determining the effectiveness of treatments or interventions for those impacted by brain cancer (N. C. Campbell et al., 2007; Paul et al., 2013; Rychetnik et al., 2002). Second, there is a need to translate the available descriptive research into interventions for brain cancer patients and SPs (Heckel et al., 2018; Huang et al., 2017; Jenkins et al., 2016; Klein et al., 2003; Laack et al., 2005). There is emerging evidence for approaches in improving psychosocial outcomes in other cancer types, such as breast cancer as well as other patient groups, including people

with stroke and dementia (Carlson & Bultz, 2003; Cheng et al., 2014; Parker et al., 2008). These include psychoeducation, cognitive behavioural therapy, comprehensive informational and clinical support including out-of-hours contacts and practical (financial, legal, employment) support and peer support (Carlson & Bultz, 2003; Catt et al., 2008; Sherwood et al., 2016). However, further work is needed to test the acceptability and effectiveness of these approaches in brain cancer populations (Janda et al., 2006; Sterckx et al., 2013). Given the impact that cancer can have on SPs and the reciprocal relationship between the outcomes of patients and SPs (Sherwood et al., 2016; Sterckx et al., 2013), programs directed solely towards improving patient outcomes may not be sufficient to meet patients' needs because so much of their care depends on SPs (Halkett et al., 2018; Sherwood et al., 2016; Sterckx et al., 2013). Therefore, a 'dyadic' approach that supports all those affected by brain cancer to cope effectively and maintain quality of life warrants further examination.

Limitations

There are several limitations to consider in this review. This review did not include grey literature, dissertations, case studies or policy documents as it was assumed unlikely that these sources would offer high-quality, rigorous, peer-reviewed evidence. The review focuses on the broad pattern of research output rather than the content or findings within each study, however other reviews focusing on content exist in the area, with this review instead highlighting a clear need for increased intervention studies aimed at improving the psychosocial wellbeing of people with brain cancer and their SPs. As there was a small number of intervention studies meeting eligibility and study design criteria, it was deemed inefficient to attempt to provide meaningful comparative data or meta-analysis for this topic.

Conclusion

The number of publications focusing on psychosocial wellbeing of people with brain cancer and their SPs has significantly increased in the last 21 years. However, a majority of these publications are descriptive in nature, with very few measurement studies or trials of interventions aimed at improving the psychosocial outcomes of this population. Furthermore, less than half of the published trials met minimum research design criteria. To increase high-level knowledge to guide the psychosocial care of people with brain cancer there is a need to develop and utilise robust measures of psychosocial well-being and undertake methodologically strong intervention trials.

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Conflicts of interest. There are no conflicts of interest.

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

Authorship contribution. All authors conceived the study design and methodology. Author 1 and 2 contributed to data acquisition and analysis. All authors contributed to the interpretation of study findings, have read and approved the final version.

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Table 1. Intervention Studies Meeting EPOC Design Criteria

Author, Year	N	Participant/Setting	Intervention	Main Outcome Measured	Main Findings	Study design
Boele et al., 2013[31]	56 SPs	Patients (with a diagnosis of high-grade glioma) and SPs were recruited via three tertiary centres for neuro-oncology patients in the Netherlands.	The intervention group received six 1-hour psychoeducation sessions. The sessions covered disease-specific information, everyday problems and cognitive behavioural therapy to cope and manage in the role as caregiver. Caregivers selected topics from a list of options, tailoring the sessions for their needs and the specific issues they were experiencing. Comparison: standard care	The main outcome measures were quality of life (QoL) and caregiver mastery. SPs also completed QoL, cognitive and neurological functioning questionnaires (patient by proxy). Caregiver QoL was assessed using the short-form health survey (SF-36), caregiver mastery was assessed using the Caregiver Mastery Scale. Caregivers completed the MOS	There was a statistically significant change in mental functioning between the intervention and control groups ($p = 0.046$). In the intervention group, mental functioning remained stable over the 5 time points whereas mental functioning in the control group declined over time.	2-arm RCT

				subjective cognitive functioning scale and Brain Cancer Module (BN20) by proxy on behalf of the patient.		
Boele et al., 2018[32]	89 patients	A broad recruitment method was utilised for this study. Patients were recruited over 3 years from 31 hospitals in the Netherlands. The study was advertised on websites and via other informal methods. Each interested individual was screened using an	The intervention group were provided with five online modules and access to an online 'coach' (psychologist, nurse or trained student). The coach provided feedback on completed activities and provided additional support if necessary. Comparison: There were two comparison groups. One was standard care, waitlisted to receive intervention	The primary outcome was depression assessed via the Centre for Epidemiological Studies Depression Scale (CES-D). The secondary outcomes were fatigue; assessed via the Checklist of Individual Strength (CIS), HRQoL assessed with the Short-Form Health Survey (SF-36) and Cognitive Functioning assessed via the MOS	No statistically significant differences were found between the groups for depression. There was a slight decrease in fatigue from baseline to follow up (p=0.054). There were no statistically significant differences between the two glioma groups however the non-CNS group reported improved HRQoL at	RCT with wait-list control

		online questionnaire prior to being included in the study.	at completion of data collection (diagnosed with glioma). The other group were non-CNS cancer controls who received the intervention at the same time as the intervention group.	cognitive functioning scale. Patient satisfaction, usability and acceptability of intervention and use of supportive care was also recorded.	the 12 month follow-up (p=0.035).	
El-Jawahri et al., 2010[33]	50 patients	Consecutive patients with a diagnosis of malignant glioma recruited at hospital outpatient oncology clinics in USA.	The intervention group viewed a video after receiving a verbal narrative. The verbal narrative described three levels of medical care in advanced cancer; life-prolonging care, basic medical care and comfort care. Followed by a 6-minute video, a visual	The primary study outcome was participant preference for care (assessed via questionnaire including 6 knowledge items); the secondary was participants' uncertainty regarding decision-making. The intervention group had an additional measure	Intervention group was significantly more likely to select comfort care and avoid CPR, were more certain of their decision and had a significant increase in knowledge score compared to control group.	2-arm RCT

			representation of the same topic viewed on a portable computer. Comparison: Verbal narrative only.	of comfort level after viewing the video (3 items on 4-point Likert scale).		
Khan et al., 2014[34]	106 patients	Patients were recruited as part of a larger rehabilitation program for glioma survivors at a tertiary referral centre in Australia.	Participants in the intervention group were given tailored multidisciplinary rehabilitation for 6-8 weeks. The program was intensive, patient-centred, individualised and goal-oriented. Delivered in half hour blocks 2-3 times per week for 6-8 weeks. Comparison: Standard care and a wait of 2-3 months for the intensive	The primary outcome was activity limitation, assessed with the Functional Independence Measure (FIM). Secondary outcomes were symptoms of anxiety, depression and stress (assessed with the Depression, Anxiety and Stress Scale, DASS), Perceived Impact of Problem Profile (PIPP) and Cancer Rehabilitation	At the 3-month follow-up the intervention group had improved scores compared to the control group for four subscales of the FIM including the communication ($p<0.01$) and psychosocial subscales ($p<0.05$). At 6 months the improvement was maintained in three of the subscales including communication ($p<0.01$) but not for	NRCT with wait-list control. Participants were allocated based on their clinical needs as determined by the treating team

			rehabilitation (same as usual wait time).	Evaluation System (CARES).	psychosocial. No significant difference was found in the other subscales.	
Locke et al., 2008[35]	19 patient and SP dyads	Patients (and their SPs) with newly diagnosed primary brain tumours undergoing radiotherapy with mild-to-moderate cognitive impairment recruited by a neuropsychologist at an outpatient clinic in USA.	The intervention group were given educational sessions to use a specialised calendar to aid and compensate for cognitive symptoms. Dyads completed six 50-minute sessions in a 2-week period. Cognitive rehabilitation and problem solving techniques were also delivered to the dyads. Comparison: standard care	The primary study outcomes were quality of life and functional capacity. Assessed via Functional Assessment of Cancer Therapy - Brain (FACT-BR, completed by patient only) and The Mayo-Portland Adaptability Inventory (MPAI-4, completed by patient and SP). Secondary outcome measures were used to further assess QoL, cognitive function, caregiver	There was no statistically significant difference between the control and intervention group or across any of the three time points for any of the outcome measures. Participants reported high satisfaction and acceptability of the intervention.	NRCT. This study did not randomise all dyads therefore it has been labelled NRCT

				burden, fatigue and mood. Satisfaction and acceptability of the intervention was assessed via questionnaire		
Ownsworth et al., 2014[36]	50 patients	Participants were recruited from hospitals and community support services in an Australian state over 2 years.	The intervention consisted of 1-hour weekly sessions over ten weeks with a psychologist. Modules covered goals, life situation, cognition, support, psychoeducation and psychotherapy. The sessions were home based and included family or SPs for some sessions.	The main outcomes were QoL assessed via the McGill Quality of Life Questionnaire (MQOL) and the Functional Assessment of Cancer Therapy - Brain subscale (FACT-Br). Symptoms of depression and anxiety were also assessed via the Depression, Anxiety and Stress Scale (DASS) and the Montgomery-Asberg	At the completion of the 10-week program, the intervention group reported significantly higher scores for existential and functional wellbeing (MQOL), higher global quality of life (FACT-Br) and lower levels of depression (MADRS) compared to the control group. 6 months after the program, participants	RCT with wait-list control

			Comparison: Standard care, waitlisted to receive intervention at completion of data collection.	Depression Rating Scale (MADRS)	reported better psychosocial outcomes than baseline including lower levels of depression and stress and increased existential well-being and global quality of life.	
Xiao et al., 2018[37]	78 patients, 78 family members	Brain tumour patients post-craniotomy recruited at time of discharge from a single hospital and a family member (spouse, child or parent of the patient - selected in that order).	Designated continued psychological care (CPC) team member delivered program to patient and family. This program included home visits and individualised care plans. Delivered in conjunction with the regular telephone follow-up schedule and provision of the Health	The main outcomes were anxiety and depression (measured using the self-rated anxiety scale (SAS) and Self-rated depression scale (SDS)) as well as treatment compliance and seizure incidence (assessed via data collected in the Health	The SAS and SDS scores were significantly lower for the intervention group compared to the control group at T2 to T4 follow-up times ($p<0.05$). The control group exhibited no significant difference at T2 to T4 compared to at T0 ($p>0.05$). This	RCT

			Monitoring Handbook for Brain Tumour Patients and health guidelines. Comparison: The comparison group received the regular telephone follow-up schedule and provision of the Health Monitoring Handbook for Brain Tumour Patients and health guidelines. They did not receive the CPC program or home visits.	Monitoring Handbook for Brain Tumour Patients).	was similar for patients and family members. Scores for treatment compliance and regular consultation compliance was significantly higher and seizure incidence was significantly lower for the intervention group compared to the control group ($p<0.05$).	

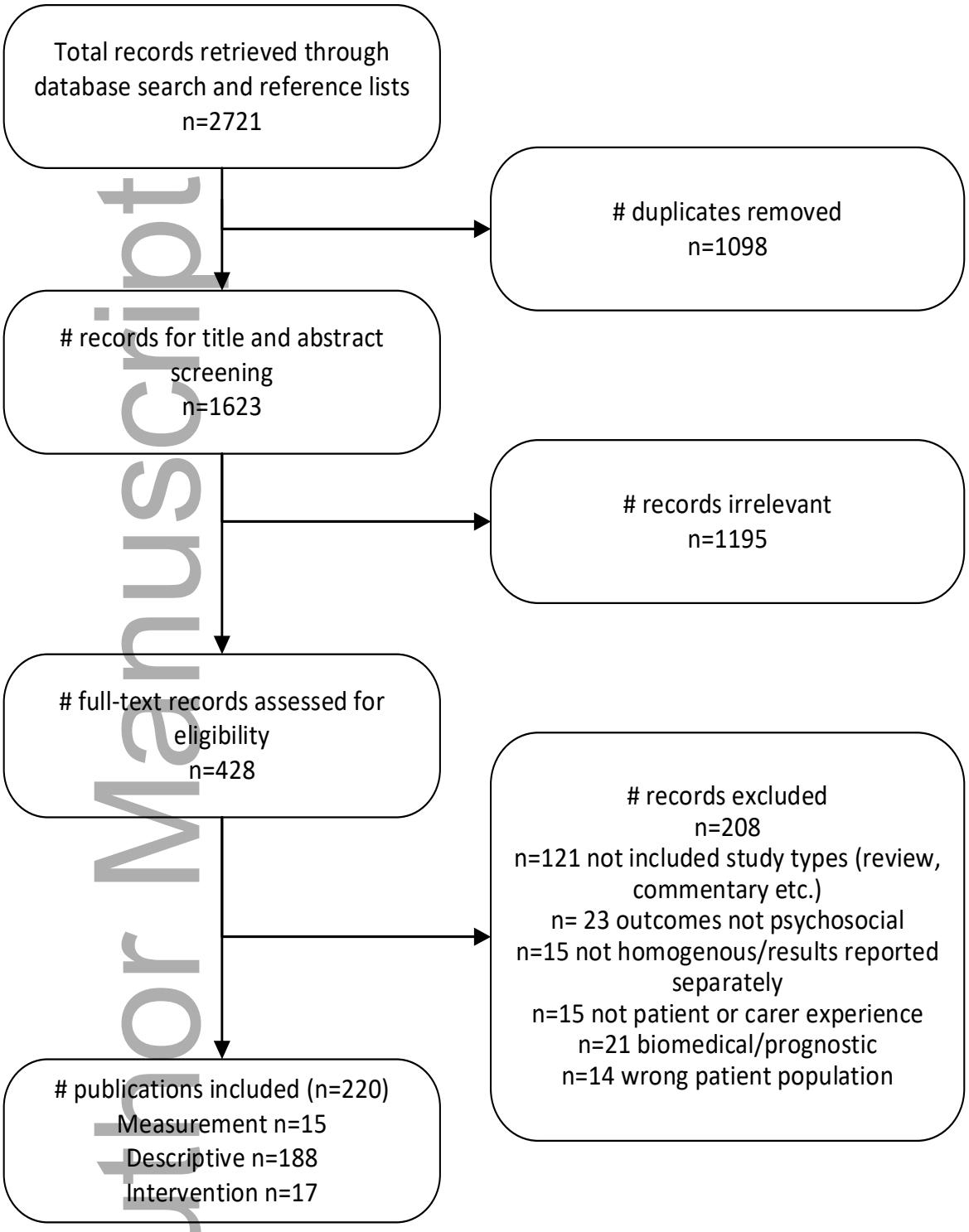

Fig 1 Search strategy

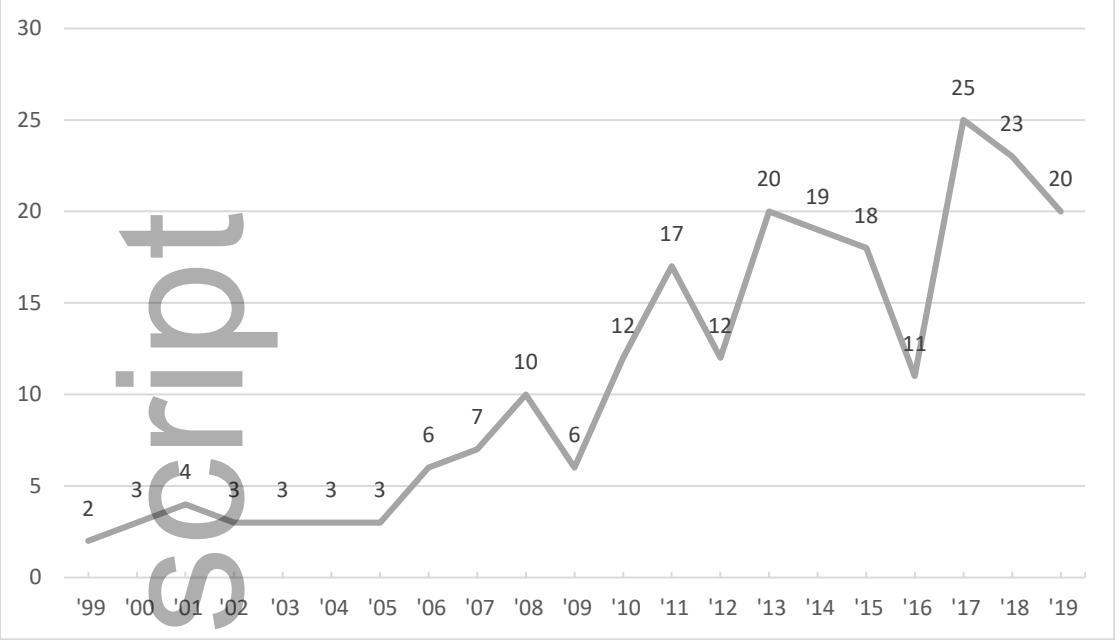

Fig 2 Number of publications by year (1999 – 2019)

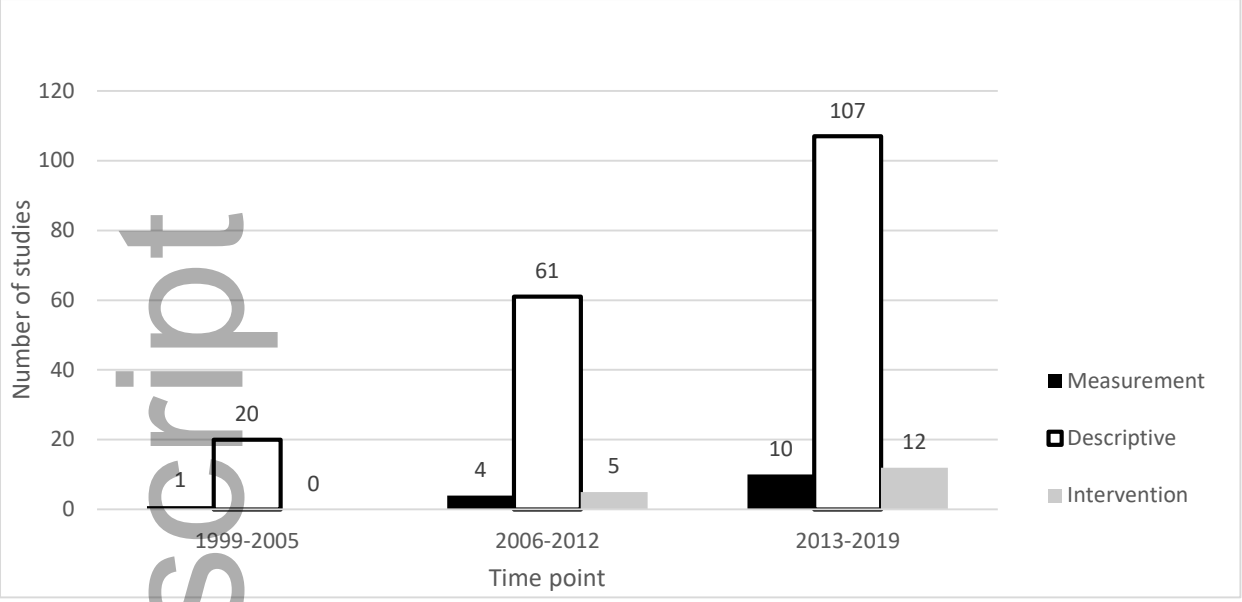

Fig 3 Type of studies at three time points