Do psychological flexibility, self-compassion, spirituality, and time-since diagnosis predict mental wellbeing in UK adults living with a primary malignant brain tumour?

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Title of degree programme	**Professional Doctorate in Clinical Psychology**
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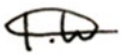
Declaration and signature of candidate
I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work. I confirm that the decision to submit this thesis is my own. I confirm that except where explicitly stated, the work has not been submitted for another academic award. I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis. Signed:  Date: 28.04.25

Acknowledgements

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Thesis Abstract

Paper one is a literature review that explores psychological and spiritual interventions that aim to address anxiety, depression, quality of life, and existential wellbeing for people living with a malignant brain tumour (MBT). Ten studies were identified, critically appraised for quality and results synthesised. The review highlighted all studies apart from problem-solving therapy improved depression, and all measuring anxiety, QOL, and spirituality saw improvements. Methodological limitations of the included studies were noted, including study design, sampling, and potential bias, along with limitations of the review itself. The results align with UK guidance for cancer care and reiterate the importance of a biopsychosocial-spiritual approach for this population. Further trials of psychological and spiritual interventions supporting emotional and existential wellbeing for MBT are recommended.

Paper two reports on a cross-sectional quantitative study investigating whether psychological flexibility, self-compassion, spirituality, and time-since diagnosis predict wellbeing in a UK sample of participants with a primary malignant brain tumour (PMBT) whilst controlling for age and gender. Ninety-five participants were recruited. Multiple regression analysis revealed psychological flexibility, spirituality, time-since diagnosis, and being male were significant predictors of wellbeing. Self-compassion was significant using the two-factor scoring but not the mean score. Age did not influence wellbeing, meaning the findings hold regardless of age. The findings suggest timely interventions targeting psychological flexibility, spirituality (meaning and purpose), and self-compassion might benefit the wellbeing of people with PMBT. The relationship between wellbeing and gender

and self-compassion merit further exploration. Further clinical and research implications and recommendations are suggested.

The final paper is a summary of paper two, written in an accessible format for study participants, anyone living with PMBT, and those supporting them. This was done with the invaluable support of two participants and the Patient Involvement Officer and Impact Lead at Brainstrust (UK charity).

Contents

Paper 1: Literature Review

What is the efficacy of psychological and spiritual interventions for anxiety, depression, quality of life, and spirituality for adults living with a malignant brain tumour?

Word count: 7996

Including summary table. Excluding other tables, figures, title page, references, and appendices.

This literature review has been written in accordance with author guidelines for the Journal of Neuropsychological Rehabilitation. Author guidelines are in Appendix A.

Abstract

Malignant brain tumours (MBT) impact mental health, quality of life (QOL), and existential wellbeing resulting from the accompanying impairments and poor prognoses. Psychological and spiritual interventions can improve emotional and spiritual outcomes and reduce healthcare costs. One systematic search of seven databases on psychological interventions for MBT since 2015 and spiritual interventions to-date was conducted in May 2024. From the 466 papers identified, ten met inclusion criteria. These were critically appraised for quality. Their impact on depression, anxiety, QOL, and spirituality were synthesised. Six were RCTs, two were single-case experimental designs (SCEDs), one was a single-arm trial, and one a mixed-methods pilot. Most interventions aligned with either NICE recommendations for supporting spirituality (reminisce and dignity therapies) or psychological wellbeing (CBT, meditation, ACT). Two interventions aligned with both ('CALM', Managing Cancer and Living Meaningfully, and 'MAST', the Making Sense of Brain Tumour program). All studies apart from problem-solving therapy improved depression. All studies measuring anxiety, QOL, and spirituality saw improvements. The results that both psychological and spiritual interventions improve outcomes in this population aligns with emerging guidance for cancer-care pathways in the UK and reiterates the importance of adopting a biopsychosocial-spiritual model for patients. It is vital to continue trialling psychological and spiritual interventions to support emotional and existential wellbeing for people with MBT.

Introduction

As the prognoses, treatment, and impact of brain tumours vary, Baker et al. (2016) suggested researching malignant (cancerous) and non-malignant separately. This review focused on malignant brain tumours (MBT), accounting for 28.3% of all brain tumours (Ostrom et al., 2015). Whilst rare, with 12,746 cases in the UK each year, MBT has one of the worst cancer survival rates, with just 11% of those diagnosed living more than 5 years (Cancer Research, 2023). Cancer Research UK estimates more females are affected by MBT. However, worldwide statistics suggest the opposite ratio (Cancer Research, 2015; Kalan Farmanfarma, 2019).

The World Health Organisation historically classified brain tumours (BT) according to growth and malignancy (Louis et al., 2016). Generally, grades I-II were slow-growing low-grade malignancies and high-grades (III-IV) grow more aggressively and have shorter prognoses (Philips et al., 2018). However, the current World Health Organisation classification emphasises molecular diagnostics over grading (WHOCNS5; Louis et al., 2021). Glioblastoma Multiforme (GBM) account for 49% of MBTs (Schaff & Mellinghoff, 2023), are the most common MBT, and have poor prognoses (Philips et al., 2018).

The 'grim prognosis' and high disease burden of MBT affects quality of life (QOL), particularly in psychological, physical, and social domains (Baumstarck et al., 2018). Fatigue, treatments, historic mental ill-health, and cognitive, functional, motor, and performance-status impairments also impact QOL (Baker et al., 2016). As does lower education and employment loss which MBT patients are vulnerable to due to impairments and rapid decline (Halkett et al., 2015).

Poor QOL, tumour site and size, and the emotional and physical experiences of diagnosis and treatments impact psychological distress (Gibson & Graber 2020; Kangas, 2015; Pelletier et al., 2002). In turn, QOL is also impacted by untreated emotional symptoms (Mathiesen et al., 2003). Of people living with MBT, 38-48% experience psychological distress (Ford et al., 2012; Gibson & Graber 2020). A survey conducted by The Brain Tumour Charity UK and Alterline (2015) revealed 91% of people with MBT report negative impacts on mental health, with many not feeling prepared for how life may change after diagnosis and treatment. Tumour detection is reported as the most distressing experience (Goebel, von Harscher, & Mehdorn, 2010), likely due to the 'double threat' posed by an MBT diagnosis: poor prognoses threaten survival, and behavioural and personality changes threaten one's sense of self (Ownsworth, 2016). After diagnosis, 15-20% of people with glioma develop depression (Rooney, Carson & Grant, 2011; Rooney et al., 2013). Depression in MBT is associated with shorter survival (Noll, Sullaway & Wefel, 2019). A recent systematic review calculated prevalence of depressive symptoms at 21.7%, suggesting the importance of MBT treatment to improve prognosis and QOL (Huang et al., 2017). The authors note this statistic is 13-18% higher than non-clinical populations, hypothesising this is due to treatment effects and awareness of disease state. It is lower than other cancers and chronic illness however, potentially due to rapid disease progression. Risk factors for developing depression in cancer include functional limitations, being younger, and lack of social support (Gibson & Graber 2020). These risks are relevant for MBT as functional impairments are common (Rooney, Carson & Grant, 2011), 48-56% of GBM occur in 40–64-year-olds (Tan et al., 2018), and social support may diminish as patients become less engaged in society (Munoz et al., 2008).

People with MBT have higher rates of anxiety compared to other cancers, estimated at 21.5% (Zeilinger et al., 2022). Trauma, demoralisation, and metastasis are more prevalent in those with anxiety (Gibson & Graber 2020). These are likely in MBT, given the potential trauma of diagnosis (Goebel et al., 2010) and disheartening prognoses (Philips et al., 2018). Whilst MBT may have spread from other parts of the body (secondary), primary MBT are less likely to metastasise (Hamilton et al., 2014); however, concerns about metastasis may be present.

The psychological experiences and their impact on QOL and survival (Batty et al., 2017) make living with MBT a unique and complex experience of high clinical importance. In 2015, Kangas reviewed psychotherapeutic interventions for this population. Four RCTs evaluating psychosocial, cognitive rehabilitation, and problem-solving interventions were reviewed; two were specific for BT. The Making Sense of Brain Tumour program (MAST) addresses psychological and spiritual needs of MBT over 10-sessions and was found to improve depression, QOL, and existential wellbeing. The second BT-specific intervention which combined problem-solving and cognitive rehabilitation found no effect. The other non-BT-specific interventions were multidisciplinary support with physical exercise, relaxation, and problem-solving. These maintained QOL but did not impact depression and anxiety. The author called for further research given only four studies originating from USA and Australia were found and only two of these were BT-specific. In the same year, Jones, Ownsworth and Shum (2015) reviewed 13 papers when introducing another MAST study, comprising case studies, single-arm studies, and RCTs (including their MAST programme reviewed in Kangas, 2015). As well as MAST, the case studies on psychosocial and peer support yielded positive results. Therefore, there is merit in exploring the effectiveness of

psychological interventions for MBT researched since 2015, excluding cognitive rehabilitation. Whilst cognitive impairment is a cause of distress, and cognitive rehabilitation is recommended, there is a recent systematic review on this (Zhao et al., 2020). Moreover, the cognitive rehabilitation studies in Jones, Ownsworth & Shum (2015) did not positively impact psychological wellbeing.

Whilst Kangas (2015) highlighted the importance of MBT-specific interventions, there exist no specific guidelines for improving psychological symptoms in MBT. The current review thus focuses on the efficacy of psychological interventions in MBT recommended for depression and anxiety for long-term conditions and the general population. To treat depression in both, the UK's National Institute for Health and Care Excellence (NICE) recommend Cognitive Behavioural Therapy (CBT), problem-solving, short-term psychodynamic psychotherapy (STPP), interpersonal psychotherapy (IPT), guided self-help, group mindfulness, and meditation (NICE, 2022; NICE, 2019). For anxiety disorders, NICE recommend CBT, self-help, and psychoeducation (NICE, 2020). Whilst Acceptance and Commitment Therapy (ACT) is not specified in NICE guidelines it is classified as a 'third-wave' CBT (Hayes & Hoffman, 2017) and thus included in this review. CBT, ACT, mindfulness, STPP, and IPT have improved depression and anxiety in cancer survivors (Blanco et al., 2014; Çitak et al., 2021; Li et al., 2021; Xunlin et al., 2019; Zhang et al., 2022).

People living with MBT can experience death anxiety, with symptoms and functional losses viewed as representations of dying (Adelbratt & Strang, 2000). Whilst 'anxiety' implies worry about imagined events, the threat of death in MBT is real, with the second lowest survival rates of all cancers (Nuffield Trust, 2024). As people with MBT face physical, functional, and psychological challenges, they may also face existential crises as death

becomes a possibility and 89% begin palliative care within five years (Cancer Research UK, 2023). Existential distress arises from events challenging beliefs and expectations about life, manifesting in fear, hopelessness, and shame (Vehling & Kissane, 2018). Existential wellbeing refers to a sense of inner peace, reverence for life, and connectedness to others. Spiritual wellbeing can involve religious and non-religious practices (Ownsworth & Nash, 2015). Whilst spirituality is difficult to define and thus study, de Brito Sena et al.'s (2021) review of definitions culminated in the following: 'a connection with something that promotes meaning and personal growth'. This definition is used in the current review, with 'spirituality' encompassing spiritual and existential wellbeing. Spirituality is associated with better emotional wellbeing and QOL in MBT (Pelletier et al., 2002; Randazzo et al., 2014). Finding meaning in adversity protects against depression and anxiety in cancer (Gustavsson-Lilius et al., 2007). It is therefore of interest to explore spirituality addressed within interventions as a separate outcome.

As per psychological interventions, there are no specific guidelines for supporting spirituality in MBT. NICE guidelines for palliative care recommend psychological, social, and spiritual support for people living with cancer. Spirituality is defined as 'the search for existential or ultimate meaning in life' (NICE, 2019). Coupled with de Brito Sena et al.'s (2021) definition, the current review included interventions related to existence, meaning, and growth, and their impact on QOL, anxiety, depression, and spirituality in MBT. Interventions including meaning-centred psychotherapy, dignity therapy, supportive-expressive group therapy, and narrative interventions have been found to be beneficial for cancer patients (Bauereiß et al., 2018). Whilst NICE recommend social support, it was not deemed a psychological intervention and thus not explored. To the author's knowledge,

there are no systematic reviews on spiritual interventions to-date, thus no date limiters were applied.

Pharmacological treatments and exercise are also recommended for anxiety, depression, and end of life care (NICE, 2022, 2020, 2019) but are not psychological interventions and thus excluded. 'Counselling' is recommended but not defined specifically, thus it was deemed too broad to define and include in this review.

Rationale

Recognising the importance of addressing spiritual and psychological needs of those with MBT, the current review explored research on interventions addressing either and both. This review has the potential to extend existing knowledge (Kangas, 2015) on the efficacy of interventions targeting psychological experiences of MBT to the present day. It also aims to provide insight on interventions addressing spirituality in a population facing short prognoses and rapid decline, an area yet to be reviewed. As the review identifies which interventions impact psychological and spiritual wellbeing, studies quantitatively measuring these outcomes were included. Whilst useful, it is harder to determine and compare impact from qualitative results.

Research question

What is the efficacy of psychological and spiritual interventions for anxiety, depression, quality of life, and spirituality for adults living with MBT?

Method

Search strategy

The author completed a systematic search in May 2024 on the following databases: Medline, CINAHL, APA Psych Info, Web of science, Cochrane library, and Google Scholar. Using a range of databases reduces the likelihood of omitting relevant papers. Haddaway et al. (2015) suggest reviewing the first 200 papers from a Google Scholar search, given the large number of results usually returned. Reference lists were screened for potential papers because hand-searching can yield additional results. Proquest, a database of dissertations, was searched for unpublished literature. This process ensures any relevant unpublished studies are included to avoid publication bias (Fanelli, 2012); however, none were found. As this is a growing area of research, randomised-controlled trials (RCTs) and non-RCTs were included, as were interventions specific to MBT and generic cancer populations.

The author agreed the following search terms and Boolean with guidance from an academic librarian: ((“Cognitive behavio?r* therapy” OR “Cognitive therapy” OR “Behavio?r* therapy” OR “Acceptance and commitment therapy” OR “Third wave CBT” OR “Behaviour* activation" OR “problem-solving” OR “guided self-help” OR “Interpersonal psychotherapy” OR IPT OR “Short-term psychodynamic psychotherapy” OR STPP OR Psychoeducation OR spiritual* OR meaning OR existen* OR “personal growth”) AND (Anxiety OR Depression OR “Quality of Life”) AND ("Brain tumour" OR “Primary brain tumour” OR “brain neoplasm” OR Glioma OR Glioblastoma OR Astrocytoma OR Anaplastic OR Oligodendroglioma OR Anaplastic OR “Diffuse midline glioma” OR “diffuse intrinsic pontine glioma” OR “Primary malignant brain tumour” OR “Optic nerve glioma” OR Ependymoma OR Anaplastic OR ependymoma OR Medulloblastoma OR Meningioma OR

"Atypical meningioma" OR "Anaplastic meningioma") NOT (child* OR p?ediatric)). One search with these terms was conducted, then papers related to psychological interventions published before 2015 were excluded manually.

Inclusion and exclusion criteria

To be reviewed, studies needed to:

- Be peer-reviewed (to improve validity of included studies).
- Be in English, due to lack of translation resources.
- Explore, either:
    - A NICE-recommended psychological intervention for anxiety and depression since 2015;
    - A spiritual intervention (as previously defined) at any time-point.
- Include adult participants (over 18 years) with MBT.
- Report quantitative findings regarding anxiety, depression, QOL, and / or spirituality (as defined).

Studies were excluded if the intervention was:

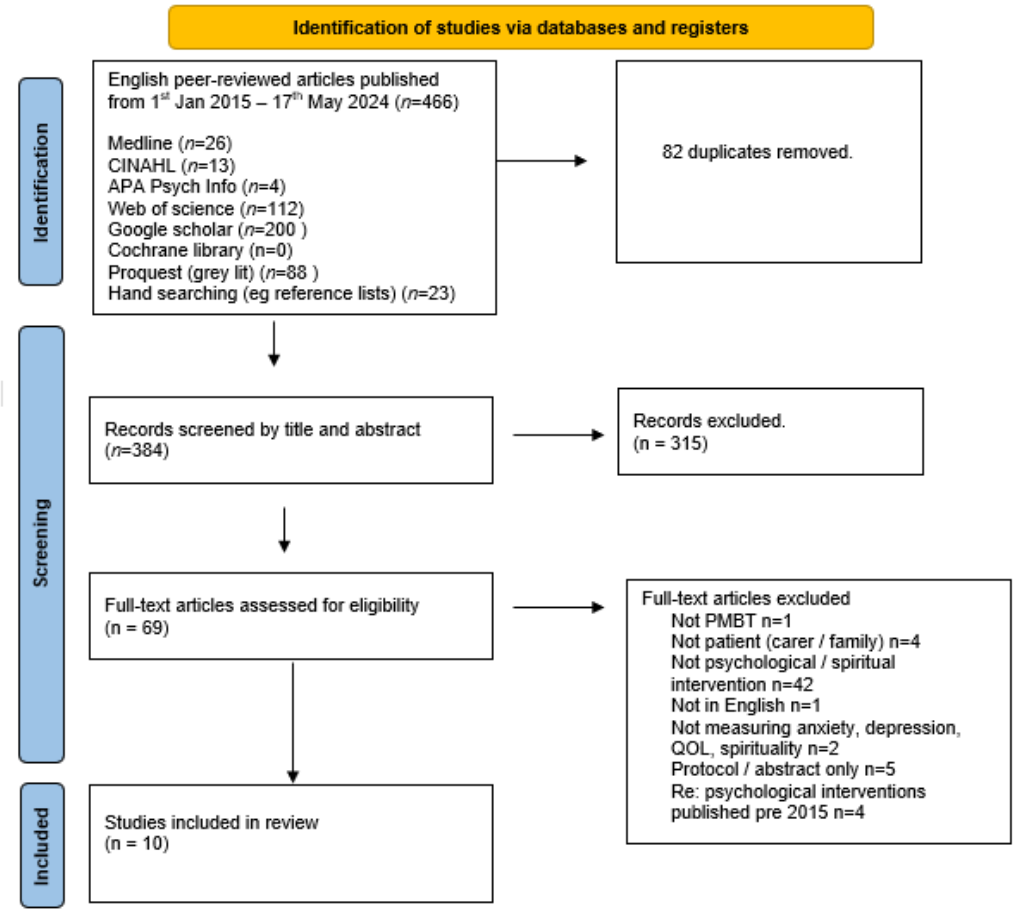
- For family members or carers only.

Paper selection and data extraction

The initial search yielded 466 results. Eighty-three duplicates were removed, either automatically by the database or manually by the author. Three-hundred-and-eighty-four titles and abstracts were screened before 69 full-text articles were assessed according to inclusion and exclusion criteria. Ten studies were included for review. Figure 1 details this search process (Liberati et al., 2009). Table 1 outlines the extracted data of the included

studies in chronological order, including authors, date, location, independent variable (intervention), dependent variables (outcomes), methods, and key findings.

Figure 1: PRISMA 2020 flow diagram for systematic reviews (Page et al., 2021)



Critical Appraisal

The Downs and Black Checklist (Downs & Black, 1998) was used to appraise study quality given the variety of quantitative approaches used (RCT, *n* = 5; non-RCTs, *n* = 2; single-case experimental designs SCED: *n* = 2; mixed methods, *n* = 1). Only the quantitative aspects of the mixed-methods study were relevant for this review thus the same checklist was used for all papers. The checklist has adequate psychometric properties, with good internal consistency, reliability, and validity (Downs and Black, 1998) and is ranked in the top six for

systematic review tools (Deeks et al., 2003). It comprises 27 items, addressing key methodological components namely, power, reporting, validity through bias, and confounding variables. Items are rated 1 if they meet the criteria and 0 if they do not or insufficient information has been given to determine. One item is rated 2 (fully met) 1 (partially) 0 (not met).

Many systematic reviews modify question 27 regarding statistical power, originally out of 5, awarding 1 point if a study had sufficient power to detect a clinically important effect; 0.5 if an analysis was done but the study was underpowered; 0 if no power analysis was conducted (O'Connor et al., 2015). A percentage of total scores was calculated as not all criteria were relevant to each study type (Hooper et al., 2008). For example, questions pertaining to randomisation in the single-arm study were not included in the total score. As it is possible, and improves quality, to randomise SCEDs (Tanious & Ongena, 2019), the first questions on randomisation were included for SCEDs. However, subsequent randomisation and blinding questions were excluded. Percentages allowed for comparison across studies and a quality rating was awarded accordingly (excellent ≥93%, good ≥71%, fair ≥54%, and poor ≤53%; Hooper et al., 2008).

Analysis

Given the heterogeneity of studies, a qualitative narrative synthesis was conducted using Popay et al. (2006) guidelines.

Results

From this point, numbers in brackets refer to the studies numbered in Table 1.

Study characteristics

The studies reviewed were published between 2014 and 2023. Nine included exclusively participants with BT. One included participants with other cancers, in which participants with MBT made up 5% of participants (Study 1). One study used a control group of participants with non-central nervous system cancers (4). Six studies were RCTs (1, 4, 5, 6, 7, 10), two were SCEDs (2, 3), one was a single-arm trial (9), and one a mixed-methods pilot (8). The latter conducted a qualitative analysis of participant experiences, but only the quantitative section was reviewed aligning with review objectives. Two studies employed interventions addressing spirituality, through dignity (1) and reminiscence (6) therapies which explore meaning, purpose, and legacies. Four interventions aligned with NICE-recommended psychotherapies for anxiety and depression (ACT *n* = 2, problem-solving / low-intensity CBT *n* = 2, mindfulness *n* = 1). Two interventions aligned with both spirituality and CBT: MAST (3, 8, 10) and CALM (9). As per review objectives, all studies quantitatively measured the impact of the intervention on depression (*n* = 7), anxiety (*n* = 5), QOL (*n* = 4), and/or spirituality (*n* = 2). Studies achieved this by comparing data between-groups (1, 4, 5, 7, 8, 10), within-subjects at different time-points (2, 3, 7, 8, 9, 10), and through visual analysis (3). All studies cited psychometric properties of measures used, which included Hospital Anxiety and Depression Scale (HADS) for depression and anxiety, Functional Assessment of Cancer Therapy-General (FACT-G) for QOL, and McGill Quality of Life Questionnaire-Expanded Version (MQOL-EW) for spirituality.

Participant characteristics

Most studies included participants with malignant brain tumours (*n* = 9); one included non-malignant and malignant, with one participant with a malignant grade II

tumour (3). Some stated if MBTs were low or high grade (*n* = 3), glioblastoma (*n* = 2), or glioma (*n* = 6). Some specified if MBTs were primary (*n* = 2) or secondary (*n* = 1). Studies were conducted in North America (*n* = 2); Europe (*n* = 3), China (*n* = 2) and Australia (*n* = 3).

Table 1. Data extraction

Study ***Author (Date),*** ***Country,*** ***Quality rating***	**Intervention (IV)** ***Name,*** ***Category (NICE / spiritual / both)***	**Outcomes (DV) (measure)** ***Depression, anxiety, QOL, spirituality***	**Sample**	**Methodology** ***Design, Analysis***	**Key Findings** ***Re: IV – DV.***
1. Julião et al. (2014) Portugal 79% (22/28)	Dignity therapy (DT). Spiritual.	Depression (HADSd) Anxiety (HASDa).	80 patients at hospice with 6 months life expectancy. 51% male. 28-90 years old. GBM; *n* = 4.	RCT. Non-blinded. Conditions: Intervention + treatment-as-usual (TAU); TAU.	DT + TAU: significant reduction in depression and anxiety; less depressed / anxious at each timepoint. (median HADSd baseline = 14; final timepoint = 10; HASDa baseline = 10; final timepoint = 4).

				Non-parametric paired comparison tests.	TAU: Increased depression (significant; HADSd median baseline = 9, final timepoint = 10) and anxiety (not significant; HASDa median baseline = 9, final timepoint = 10).
2. Kangas et al. (2015) Germany 74% (17/23)	Manualised ACT-based programme for brain tumours (BT-ACT). (6 x 90-min weekly). NICE.	Anxiety (SCID-DSM-anxiety disorders; STAI trait & state scales) Depression	4 patients with MBT. 1:3 male:female. 39–53 years.	SCED. Pre/post comparison.	3/4 participants no longer met criteria for anxiety (STAI-trait/state: P2: baseline = 59/49, end = 31/37; P3: baseline = 50/40, end = 26/22; P4: baseline = 50/43, end = NA/32) and/or depressive disorders (BDI-II: P2:

		(SCID-DSM—MDD; BDI-II) QOL (FACT-G, FACT-BT)			baseline = 34, end = 5; P3: baseline = 23, end = 0; P4: baseline = 14, end = 0) QOL increased (FACT-G scores: P2: baseline = 30 end =73; P3 baseline = 67, end = 96; P4 baseline = 59, end = 86). 1/4: anxiety and depressive symptoms stabilised. (P1: BDI-II, baseline = 40, end = 34). Effects maintained at 3 months.

3. Jones, Ownsworth & Shum (2015) Australia 83% (23.5/28)	Tele-MAST (phone) (4 x weekly). Both.	Depression (DASS-21) Anxiety (GAD-7) QOL (FACT-Br)	4 participants with benign or malignant BT. 3:1 male:female 34–49 years.	SCED. Conditions: Staggered baselines. Pre/post comparison. Visual inspection. Tau-U.	2/4: Depression and/or anxiety significantly improved. (DASS-21: P2: Tau-*U* = −0.829, *p* = 0.005; GAD-7: P2: Tau-*U* = −0.92, *p* = 0.005; P4: Tau-*U* = −0.7, *p* = 0.002) All: Improved QOL (FACT-Br P1: baseline = 72, end = 98; P2: baseline = 66, end = 98; P3: baseline = 58, end = 71; P4: baseline = 71, end = 82)

4. Boele et al. (2018) Holland 77% (21.5/28)	Online guided self-help problem-solving therapy (PST) (5 x weekly) NICE.	Depression (CES-D) QOL (HRQOL (Short Form-36))	115 participants: 89 participants with glioma; 26 Non-CNS cancers.	RCT. Conditions: intervention, control, non-CNS cancer comparison group.	Depression: No statistically significant differences in between groups. (p = 0.454, ES = 0.038) QOL: remained stable (glioma); improved (comparison) (p = 0.349, ES = 0.132). Anecdotally beneficial.
5. Milbury et al., (2020) USA 84% (23.5/28)	Online meditation for couples (4 x 90 min weekly sessions). Both.	Depression (CES-D).	35 glioma patients (and partners). 54% male 77% white 31-75 years 63% PMBT.	RCT. Conditions: Intervention; TAU.	Significant effect sizes found for patients only. Intervention: Depression: Marginally significant improvement, medium effect (13.80 vs. 20.68;

					F = 3.91; *p* = 0.06; *d* = 0.70).
6. Zhao (2021) China 84% (23.5/28)	Reminiscence therapy-based care (RTBC). (2x month for 12 months). Spiritual.	Depression (HADSd) Anxiety (HADSa; SAS).	150 glioma patients 61.3% males Mean age: 48.7± 10.6 (RTBC) 50.8±11.3 (TAU).	RCT. Conditions: Intervention; TAU	Intervention: HASDd decreased: Month 6 (P=.049), M9 (P=.006), M12 (P=.013). HADSa descreased M9 (P=.024) and M12 (P=.010). Proportion of HADSd and HADSa patients reduced.
7. Zhao & Xu (2021)	Nursing-led CBT for 3 months.	Anxiety (SAS) Depression (SDS)	108 patients with glioma 66 males.	RCT. Conditions: Intervention; TAU	Intervention: Lower depression (pre = 48.93±6.93; post = 45.89±7.09) and anxiety (pre =

China 75% (21/28).	NICE.	QOL (QLQ-C30).	23-69 years old 42 low grade 66 high grade.		46.81±7.12; post = 39.12±6.01); higher QOL (pre = 53.70±3.14; post = 66.68±3.21).
8. Ownsworth et al. (2022) Australia 79% (22/28)	TeleMAST – video (pilot). (10 x weekly session). Both.	Depression (MADRS) Anxiety (GAD-7) Existential wellbeing (MQOL-E) QOL (MQOL).	14 participants with glioma. 71% high grade 71% male 23-70 years.	Mixed methods. Randomly allocated to intervention; TAU / WL.	Intervention: Most participants (63%) clinically reliable and significant improvements on all outcomes (MADRS: t = 3.96, p < .05, d =.75; GAD-7: t = 2.91 p < .05 d = 1.17; MQOL: t = −4.18, p < .01; d = 1.69; MQOL-E: t = −3.36, p < .05, d = 1.20).
9.	CALM.	Depression (PHQ-9) Death	14 patients with glioma	Single-arm.	Reductions in death anxiety,

Loughan et al. (2022) USA, Canada 73% (16/23)	Both.	anxiety (DADDS), Generalized anxiety (GAD-7), Fear of cancer recurrence (FCR-7), Spirituality (FACIT-SP), QOL (QOL-E).	83% glioblastoma 75% female 27-81 years.	Pre/post.	generalized anxiety (large effects: t = 2.475, p = .038, d = .825), depression (medium effect; t = 1.385, p = .203, d = .46); increases in spirituality (largest effect: t = −4.243, p =.002, d = .−1.500). QOL and fear of cancer recurrence remained stable (QOL-E: t = .254, p = .806 d = −.396; FACIT-SP: t = −4.243, p = .002, d = −1.500).
10. Ownsworth et al. (2023)	Tele-MAST video (RCT).	Depression (MADRS) Anxiety	82 participants: 34% benign	RCT. Intervention; TAU.	Significant intervention effects for depression (medium effect: F = 11.61, p = 0.001); subscales of

Australia 86% (24/28)	Both.	(GAD-7) QOL (FACT-Br).	20% lower-grade glioma 46% high- grade glioma. 61% female. mean age: 47.9 years (*SD* = 14.5).		FACT-Br (FACT-G: *F* = 6.10, *p* = 0.016, FACT-Physical: *F* = 5.30, *p* = 0.024, FACT-Emotional: *F* = 10.83, *p* = 0.002, FACT-Functional *F* = 6.60, *p* = 0.012); anxiety (GAD-7 *F* = 8.56, *p* = 0.005). All effects sustained long-term.

Description of interventions

All but one intervention (1) was specifically for people with BT, which is an improvement on interventions reviewed by Kangas (2015).

Spiritual

Dignity therapy (DT) (1) is a brief psychological approach aiming to improve a patient's sense of meaning and purpose. Patients are guided through one-hour sessions, often at their bedside, to make a record of what they want loved ones to remember of them. This includes life history, accomplishments, and advice. The process aims to helps patients feel valued and reassured something of them will last beyond death. DT was delivered by the principal investigator, supervised by a DT-trained psychiatrist.

Reminiscence therapy has positive effects in dementia populations, decreasing anxiety and depression and fostering self-identity by recalling memories. Zhao (6) applied these principles to people living with glioma alongside treatment-as-usual (TAU). Group discussions facilitated by trained nurses included childhood memories, favourite games, education, career, relationships, photos, entertainment, and culture.

NICE-recommended interventions

Boele (4) trialled a low-intensity form of CBT with guided self-help based on problem-solving therapy (PST). The five-week online programme delivered by the research team was adapted for people with brain tumours, from an existing PST course. Participants expressed what was important in their lives, made a problem list, and learnt appropriate coping strategies, supported by a coach who was a nurse, researcher, or psychology student.

ACT for brain tumours (BT-ACT) (2) is based on core ACT processes, including acceptance, de-fusion, and values, designed to address issues faced by people living with a brain tumour. Six weekly 90-minute sessions with two boosters delivered by a clinical psychologist cover mindfulness training, learning to deal with uncertainty, behavioural exercises to reduce avoidance, connecting with values, and goals.

In China, Zhao & Xu compared nursing-led CBT with TAU. Participants were assisted by nurses with communication skills, cognitive restructuring, relaxation, exercise, and nutrition. Psychoeducation for participants and relatives was offered throughout.

An online meditation programme for people with glioma and their partners delivered by the research team was trialled in 2020 (5). Informed by positive psychology, participants were introduced to mindfulness, compassion, gratitude, values-based living, and guided to bring these principles (e.g., non-judgmental presence) to sharing with each other.

Both

Recognising both the psychological and existential impact of living with MBT, Ownsworth and colleagues developed, researched, and refined interventions addressing both spirituality and psychological symptoms in MBT (Ownsworth and Nash, 2015). The first RCT of the in-person MAST programme was included in the aforementioned literature review (Kangas, 2015). Three studies in the current review researched this intervention delivered since 2014 by telephone (3) and video (8, pilot; 10, RCT). The manualised programme of 10 one-hour weekly sessions is delivered by a psychologist. Participants first tell their story of diagnosis and treatment then highlight values and goals. Sessions include

managing negative emotions, cognitive difficulties, relationships, and healthy behaviours with psychoeducation, cognitive rehabilitation, mindfulness, and existential discussions.

Managing Cancer and Living Meaningfully (CALM; 9) is a brief intervention supporting people with advanced cancer to adapt to challenges of the disease and treatments whilst remaining engaged in life and preparing for death. This approach also aligns with both ACT and spiritual concepts. Sessions address symptom management, communication with professionals, interpersonal relationships, meaning, purpose, hope, and mortality. Trained, empathic therapists promote self-understanding, allow emotions to arise and be tolerated, supporting patients to have awareness of both life's possibilities and the eventuality of dying.

Study Quality

Using the percentage approach (Hooper, 2008), all studies were rated 'good', with a mean average of 79%. However, as it is possible to randomise all but one methodology (single-arm) and some items were not relevant for one of the SCEDs, all items could have been included in the final analysis for 8 studies. Using raw scores results in two studies being rated as fair (2, 9), with a mean average raw score of 21.3/28 (range 16–24). None obtained 'excellent' ratings using raw scores or percentages.

All studies clearly stated their aims, outcomes, participant characteristics, interventions, and findings, including reporting actual outcomes and probability. Where applicable, studies described why participants had not completed the study. All used appropriate statistical tests and valid and reliable outcome measures. Quality points were lost in not reporting adverse consequences (*n* = 10), generalisability of the sample (*n* = 5),

statistical power (*n* = 7), and blinding researchers, professionals (*n* = 9) and participants where possible (*n* = 6).

Research design

The majority of studies employed RCT methodologies using wait-list controls (WLC; 4) or TAU (1, 10, 5, 6, 7). The mixed-methods pilot (8) randomly allocated participants to intervention or TAU conditions, however with *N* = 14, this was not considered an RCT. All studies had clear timelines, illustrating an equal length of time between intervention delivery and outcome measurements in each condition, which is recommended. However, not all participants in control conditions were able to receive the intervention due to the nature of BT which is characterised by rapid, debilitating progression, and short prognoses, raising ethical questions. Whilst providing a control condition is good, the type of control is critiqued (Mohr et al., 2009). In TAU it is hard to know what the TAU is, and it can vary. Outcomes might therefore be due to extraneous variables. There is less rigorous monitoring of TAU delivery and compliance compared to experimental conditions which makes comparisons difficult. WLCs control for threats to internal validity and detect adverse experimental effects. However, they are vulnerable to variations in implementation as they are not rigorously controlled like experimental conditions. They produce large effect sizes because participants often improve with any intervention.

In SCEDs (2, 3), each case (an individual or group) is its own control, assessing outcomes before an intervention is introduced (Morley, 2017). The strongest SCED was for MAST which randomly allocated participants to staggered baselines. Despite small sample sizes, SCEDs provide practice-based evidence for new treatments (Kratochwill et al., 2013)

rooted in experimental procedure, offering insights from individual experiences (Morley, 2017).

Sample

All studies used opportunistic sampling. Researchers recruited participants through healthcare settings accessed by people with brain tumours: hospice (1, *n* = 1), hospitals (2-10, *n* = 9), and outpatient groups (4, *n* = 1). More specifically, oncology departments (2, *n* = 1), brain tumour clinics, neurosurgery departments (7, 6; *n* = 2), and community cancer or healthcare centres (3, 5, 9, 10; *n* = 4). This is assumed to generate a representative sample; however, it is recognised that health institutions are not accessed by all members of society (Tobin, et al., 2021).

Potential participants offered to take part. Whilst most ethical, opportunistic samples are generally more motivated or interested in the topic and thus have certain characteristics which mean they are not representative of the target population (Baker et al., 2013). Participant characteristics were not representative of MBT populations for four studies (1, 4, 8, 9) as recent incidence rates report higher male to female ratio, with age ranging between 41-60 years (Schaff & Mellinghoff, 2023; Tian et al., 2018). These studies were thus rated as not having representative samples. Whilst the exact age of the participants in study 1 was not reported, the authors commented that participants were 'older' and thus couldn't generalise results to younger people at end of life. It is difficult to comment whether the SCEDs were representative as one had 1:3 female to male ratio and the other 3:1. Representative sampling is important, particularly in a population like MBT where individual experiences and capacities vary.

Number of participants ranged between 4-150, with 4 the mode. This is due to the SCEDs having *N* = 4 which is appropriate for SCEDs (Morley, 2017), and the larger study of participants with other cancers (1). The mean number of participants in RCTs was 62.5 (range = 35-150). Eight studies conducted a power analysis (1, 3-7, 10), of which two were sufficiently powered (7, 10). Most studies acknowledged the impact of results being underpowered, namely replicability, generalisability, and confidence in findings (Cohen, 1992).

Risk of bias

Whilst RCTs are considered gold-standard in clinical research because the randomisation and control conditions serve to eliminate bias, they need to adhere to certain standards in design, including allocation concealment, blinding, intention-to-treat analysis, and sufficient sample sizes to be robustly conducted (Hariton & Locascio, 2018). As previously stated, similar principles could apply to SCEDs, thus all except the single-arm study were appraised under these standards.

All but one RCT concealed condition-allocation using sealed, opaque envelopes, opened as participants entered the trial or a computerised system (1, 3, 4, 5, 6, 8, 10). None of the studies blinded participants or assessors. Four used intention-to-treat analyses (4, 5, 6, 9) and just two were sufficiently powered (7, 10).

It is possible to blind participants and researchers in RCTs and SCEDs, which is important to reduce bias created by expectations, adherence to treatment, and assessment of the intervention (Monaghon et al., 2021). All studies stated lack of blinding was due to study design, as participants would know if they were receiving therapy or not. It could also be due to reduced resources, implied by researchers delivering interventions. Sometimes

assessors were independent from the study, but none were blinded. In (1), staff were blinded to avoid bias in their delivery of care based on patients' condition assignment.

The quality checklist and other researchers also consider intervention compliance (Mohr et al., 2009) and reliability of measures used. All but one (7) listed psychometric properties of outcome measures. All interventions were rated as being adhered to. All studies employed manualised interventions to facilitate compliance (Mohr et al., 2009). However, only two (1, 10) stated specifically whether therapists adhered to interventions.

Most studies were under–powered. However, a trade-off between controlling for threats to bias and statistical power is inherent to RCTs (Mohr et al., 2009). Bias control is often sacrificed for feasibility, ethics, and statistical power (Mohr et al., 2009).

Effect sizes are integral to understanding whether studies with varying sample sizes found a meaningful effect, not just statistical significance (Cohen, 1992). Only three studies provided effect sizes; one that was sufficiently powered did not (7).

Quality summary

The highest quality studies (>80%) were the SCED (3) and RCT (10) for the tele-MAST programme and the RCTs for couples' meditation (5) and reminiscence therapy (6). They had representative samples, some attempted blinding (3, 10), three clearly described confounding variables (5, 6, 10), undertook power calculations (3, 5, 6), and one was sufficiently powered (10). The strongest study was the RCT for tele-MAST (10).

Summary of findings

Depression

Spiritual interventions

Participants receiving dignity (1) and reminiscence (6) therapy reported a significant and sustained decrease in depression. The TAU condition in (1) experienced a significant increase in depression which may be due to the problems already discussed with TAU controls. These were good quality RCTs (79%, 84%), however only four of the 80 participants in (1) had MBT (glioblastoma). As their individual results were not available, the generalisability of dignity therapy for MBT is uncertain.

NICE-recommended interventions

Three of the four participants receiving BT-ACT (2) no longer met criteria for depressive disorders post-therapy, with effects maintained at 1 and 3-month follow-ups. Depression stabilised for the fourth, who had existing mental health challenges. This study was of fair quality (74%) and is a SCED. Thus, findings should be interpreted with caution. A significant medium effect for improvements in depression was found in patients (not partners) engaged in meditation (5). This study was good quality (84%).

The low-intensity CBT PST (4) was not effective in reducing depression. However, participants anecdotally reported finding it beneficial. This was the fourth lowest quality study in this review as it was underpowered, had an unrepresentative sample of more female participants who were educated, and a TAU control. However, it was still rated good in percentage and raw score (77%). A similar study in quality (75%) and intervention (7) reported lower depression for participants receiving nursing-led CBT. Slightly higher quality

studies might yield different results for both interventions, thus the efficacy of low-intensity CBT on depression cannot be clearly determined.

Both

All MAST studies (3, 8, 10) reported improvements in depression. Two participants in the good quality SCED (3) (83%) reported improvements in depression. However, the participant with a malignant tumour did not report significant changes. This could be due to the tumour location or size. Most participants receiving tele-MAST video (8) in this good quality pilot (79%) saw clinically reliable and significant improvements in depression; however, with *N* = 14 this may not be generalisable. The subsequent RCT (10), the highest rated study (86%), reported significant medium effects, with lower, sustained depression scores in the intervention group. This varied wealth of quality evidence points to MAST being an effective intervention to reduce depression in BT. The CALM study (9), of fair quality (70%), mostly because it was single-arm, found a medium effect reduction in depression.

Anxiety

Anxiety was an outcome in seven studies.

Spiritual interventions

Those receiving dignity therapy (1) had significantly lower anxiety at all assessment points. Participants in TAU reported an increase in anxiety, but this was not significant. Reminiscence therapy (6) also reduced anxiety at 9 and 12 months, however there was no difference between the intervention and control groups at other time-points.

NICE-recommended interventions

Similarly to results for depression, one participant's mental health stabilised and three of the four were not anxious post-therapy in the BT-ACT SCED (2). These effects were maintained. The participants receiving nurse-led CBT (7) also had lower anxiety. The low-intensity CBT studies (4, 7) did not report on anxiety.

Both

The MAST studies reported similar, significant gains in anxiety as with depression. Most importantly with the SCED (3) is that the participant with a malignant tumour experienced a reduction in anxiety. The video MAST pilot (8) and RCT (10) also reported a reduction in anxiety for most participants. The CALM study (9) found a reduction in death anxiety and large effects for a reduction in generalised anxiety (large effects) whilst fear of cancer recurrence remained stable.

Quality of Life (QOL)

The spirituality interventions did not report QOL outcomes.

NICE-recommended interventions

All 4 participants in the BT-ACT SCED (2) reported improved QOL. Low-intensity CBT (4) was not effective in improving QOL, although it did improve in the participants with non-CNS cancers.

Both

QOL remained stable for participants receiving CALM. However, it must be acknowledged this was a single-arm study of fair quality. As with other outcomes, participants experienced improvements in QOL including for the SCED participant with a

malignant tumour (3). The good quality RCT (10) for MAST found significantly better global, emotional, and functional QOL but no significant intervention effect for social QOL.

Spirituality

Six studies did not objectively measure spirituality. Dignity therapy being one; however, the author concluded that perhaps it enabled patients to address existential issues, such as unfinished business, resulting in reduced anxiety which was sustained. MAST resulted in increased acceptance in the SCED participant with a brain tumour (3), and significant improvements in their measure of existential QOL (MQOL-E) (8, 10). The largest effect in the CALM study (9) was in increased spirituality.

Discussion

The current review explored the effectiveness of psychological interventions aligned with NICE guidelines on anxiety, depression, quality of life, and spirituality in people with MBT. The review highlights that all but one study (4, PST) reported a decrease in depression. Although all studies were good quality in percentages, the higher quality studies (>80%) on reminiscence therapy, couples' meditation (5), and MAST (3, 10) could be given more weighting in conclusions drawn.

Not all studies measured anxiety, QOL, and spirituality as outcomes, making cross-intervention comparisons on these aspects more complex. The studies that measured anxiety (1-3, 6-10) reported improvements. The stability in fear of cancer recurrence in CALM participants may be inevitable in this population (9). This confirms interventions should, and some reviewed here did (BT-ACT, MAST, PST, meditation, nursing-led CBT), focus on managing and/or accepting the uncontrollable aspects of MBT.

Apart from PST (4), studies that measured QOL (BT-ACT, CALM and MAST) reported improvements. However, MAST saw no effect for social QOL, which could again be due to the reality of living with MBT where social aspects are significantly affected (Munoz et al., 2008). CALM and MAST also reported increased existential wellbeing. This could mean whilst fear of cancer recurrence and reduced QOL in some areas are inevitable with MBT, participants can find purpose and meaning which is as important for those with life-limiting illnesses (Amoah, 2011). It is therefore interesting that only two studies measured spirituality as an outcome. Some interventions might have positively influenced this which would support participants when depression, anxiety, and QOL are compromised.

Guided self-help and problem-solving, part of the low-intensity CBT intervention (4), are recommended by NICE for anxiety and mild – moderate depression (NICE 2020; NICE 2022). However, that intervention did not see improvements in these. This approach might not suit the MBT population, or the study was not of high enough quality to determine. The former argument could be supported by improvements seen in non-CNS cancer participants and a study included in the Kangas (2015) review where PST did not improve outcomes for MBT. Tumour size or location could also influence ongoing mood and ability to apply strategies (3), rather than the intervention not being successful. PST might not have suited MBT as CBT requires accessing and consciously changing thoughts and behaviours. This might be challenging due to potential cognitive impairments and what is thought and feared might be accurate. Third-wave options may thus be preferable and were shown in this review to yield positive results (BT-ACT; CALM; MAST). However, in a systematic review of third-wave CBT for acquired brain injury, a comparable population, Compassion-Focused

Therapy (Gilbert, 2013) was more effective than ACT (Shaw, 2020). Without any studies on CFT in MBT, comparisons between third-wave approaches cannot be made.

In contrast, the nursing-led CBT programme positively impacted depression and anxiety. Whilst of 'good' quality, this was the third lowest quality study of the review, which impacts generalisability. More research is required to determine whether CBT applies to the psychological experiences of people with MBT. If it does not, specifying evidence-based psychological and spiritual support in current NICE guidelines for this population (NICE, 2018) is required. NICE have previously been criticised for lack of guidelines for, and practice of, evidence-based cancer-specific psychological interventions (Jacobson, 2008). As 58% of people with cancer feel their emotional needs are not as well looked after as their physical needs (NICE, 2004), and providing psychological support reduces healthcare costs by 20% (Layard & Clarke, 2014), it is encouraging to know things are changing: The NHS are requesting implementation of specialist psychological support for cancer patients (NHS, 2023); their Transforming Cancer Services programme encourage psychologically-informed cancer care and suggest psychological and existential interventions for patients (NHS Healthy London Partnership, 2020); and, the Tessa Jowell guidelines integrate psychology within neuro-oncology care (Wright et al., 2024).

Limitations

The limitations of the included papers have already been highlighted, particularly in study design where blinding was possible but did not occur; the type of control conditions used; and small, unrepresentative samples leading to under-powered statistical analysis. The process and scope of this review is also open to criticism. The included papers did not represent all possible psychological interventions recommended by NICE or clinical

psychologists working in palliative care (Lagerdahl, 2024), including, person-centred and existential psychotherapies (e.g. Yalom, 2009), narrative therapies (White, 1990), and CFT. For example, self-compassion (Neff, 2003) has already been shown to reduce the impact of poor physical health (Homan & Sirois, 2017). This could be due to the author missing such papers or the absence of them in publication. NICE also recommend group and peer support and Jones, Ownsworth & Shum (2015) found positive results for case studies on this. However, only one included study was a group, but not peer-led, intervention. This spirituality intervention (5) yielded positive results in anxiety and depression and was a high-quality study. Charities often provide group and peer support but may not have capacity to research their impact. Brainstrust (UK) run such groups and have qualitative and anecdotal evidence of positive effects.

Furthermore, depression and anxiety are not the only potential psychological impacts of MBT. MBT diagnosis, treatment, symptoms and prognosis may result in trauma, although there is little research on this amongst adults (Fehrenbach et al., 2021). Whilst beyond the scope of this review, adding to the emerging literature on trauma-focussed treatments like EMDR (Dinapoli et al., 2019; Szpringer, 2018) or those maximising post-traumatic growth (Wang et al., 2018) and resilience (Fröhlich et al., 2022) in this population might be fruitful to explore. Similarly, non-psychological interventions can impact psychological outcomes in this population, with positive effects of exercise (e.g. Codier, Gerber & Brand, 2019) and yoga (Milbury et al., 2017).

Publication and reviewer bias must be acknowledged. For example, one study (Díaz Cordobés et al., 2012) was excluded due to not being available in English. Study protocols could have been included in searches to mitigate publication bias. Three of the reviewed

studies regarding the MAST intervention were led by the same author (3, 8. 10). This led to a positive conclusion drawn about MAST, due to three good quality studies implying a strong evidence-base. However, it might only mean this intervention has strong financial and institutional support. There may be interventions emerging across the globe that do not have the privilege of funding for quality studies. Similarly, eight studies were conducted in Western countries and two in China, which may also limit generalisability of findings. Finally, whilst the quality appraisal tool is widely used, valid, and reliable, literature reviews should have more than one reviewer for objectivity in rating. Whilst the author sought to mitigate the absence of this by following the procedure carefully, seeking supervision, and reporting on the process and results in appendix B for replication, quality appraisal was ultimately subjective and thus potentially biased. It is also recommended to have more than one author for paper selection and data extraction.

Clinical Implications

As all studies were good quality and all apart from PST (4) yielded positive results, it could be concluded that most approaches in this review could benefit people living with MBT and clinicians could apply those to suit individual experiences and circumstances. Although, improving the standard of research into the lower quality studies (BT-ACT, low-intensity CBT and CALM), and trialling dignity therapy in an MBT-specific sample in a better-quality study, might yield different results.

Two of the three highest quality studies which had a positive impact on depression (meditation and MAST) were interventions that aligned with NICE-recommended approaches for both depression (meditation and third-wave CBT) and spirituality in palliative care, including gratitude, meaning, and existential conversations within them. This

might mean a combination of psychotherapeutic and spiritual interventions work best for this population. The 'double threat' (Ownsworth, 2013) of MBT might require addressing both emotional and existential wellbeing. Rego and Nunes (2019) argue psychologists must adopt a biopsychosocial-spiritual model to comprehensively address all patients' needs: physical, emotional, social, and existential. These areas are all significantly affected in MBT, thus a clinical approach encompassing them is logical.

The findings also inform how MBT interventions are best delivered. The higher quality studies with positive results were for MAST delivered by telephone and video, online meditation, and an in-person reminiscence therapy group. The latter confirms NICE recommendations for group support. Flexibility in delivery is likely to benefit this population for whom mobility might be limited, thus success of tele-health platforms is useful for clinical applications. It was unclear whether partner interactions were integral to patient outcomes in couples' meditation (5). Further research could distinguish whether the success lay in individual, paired, or group meditation. Intervention facilitators varied across studies (nurses, psychologists, researchers). Whilst all received training, this may have impacted results and it remains unclear who is best delivering psychological interventions for MBT.

Whilst cognitive impairment can accompany an MBT diagnosis, some studies excluded patients with cognitive impairment. It is thus difficult to generalise results to the whole MBT population. This exclusion also highlights the necessity and complexity of devising appropriate interventions and ethical studies that include those with cognitive impairment (WHO, 2011). There are guidelines for this, and emerging evidence being gathered in dementia populations (APA 2012; Nygård, 2006).

It is also important for clinicians supporting those with MBT to understand factors beyond diagnosis influence psychological experiences including education and employment status (Halkett et al., 2015), previous mental ill-health (Baker et al., 2016), trauma, age, social support (Gibson & Graber 2020). A UK survey revealed inequalities in diagnosis and thus treatment based on gender and income (The Brain Tumour Charity, 2015). Cancer patients from marginalised and minoritised populations are at higher risk of developing psychological distress (Gibson et al., 2017). These findings and initiatives reiterate the importance of holding the 'whole person' in mind when supporting biopsychosocial-spiritual needs of people with MBT (Rego & Nunes, 2019).

The timing of interventions could also be important. Dignity therapy (1) was offered in a hospice for people with ≤6 months prognosis. Other interventions were offered to self-selecting participants at any point in their MBT journey with some level of psychological distress (2, 4, 8, 9, 10). Given the vulnerability of this population to psychological and existential distress, early intervention could be supportive. With evidence of risk factors for distress it could be possible to predict those likely to develop psychological symptoms which is useful for timely intervention. Rijnen and colleagues (2020) were able to predict cognitive impairment in GBM. However, a systematic review on predictors of emotional distress in cancer patients concluded the process is complex, but that early assessment remains key (Cook et al., 2018).

This review combined primary and secondary MBT. Baker et al., (2016) suggests as well as the difference in experience of malignant and non-malignant tumours, those with primary and secondary MBT may differ in psychological and spiritual experiences and thus

needs. Appropriate recommendations might result from exploring primary and secondary MBT separately in future interventions and reviews as the evidence-base grows.

Conclusion

This review extends findings from Kangas (2015) on psychological interventions for people living with MBT with the addition of interventions addressing spiritual aspects of living with MBT given the emotional and existential impacts. The findings indicate that both psychological and spiritual interventions can improve depression, anxiety, QOL, and spirituality for people living with MBT. PST was not effective, however, which might be due to the realities of living with PMBT, its treatments, poor prognoses, and impact on QOL. The strongest study was the RCT on MAST, which is an intervention combining psychological and spiritual components. This aligns with emerging guidance for cancer-care pathways in the UK (NHS, 2024) and Rego and Nunes' (2019) invitation for psychologists to adopt a biopsychosocial-spiritual model for all needs. Even 11 years on from the first review on the topic, this area of research is still in its infancy. With the adversity presented by an MBT diagnosis, in all domains of life, it is vital to continue building the evidence-base of psychological and spiritual interventions to support a person's emotional and existential wellbeing.

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Appendices

Appendix A: Author guidelines

Appendix B: Quality appraisal checklist

Appendix A

Manuscript guidelines for Journal of Neuropsychological Rehabilitation:

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=pnrh20

Appendix B

Quality Appraisal Checklist

DOWNS AND BLACK CHECKLIST FOR CLINICAL TRIAL QUALITY ASSESSMENT	Julião et al., 2014	Kangas et al., 2015	Jones, Ownsworth & Shum, 2015	Boele et al., 2018	Milbury et al., 2020	Zhao, 2021	Zhao & Xu, 2021	Ownsworth et al., 2022	Loughan et al., 2022	Ownsworth et al., 2023
Q1. Is the objective of the study clear?	1	1	1	1	1	1	1	1	1	1
Q2. Are the main outcomes clearly	1	1	1	1	1	1	1	1	1	1

described in the Introduction or Methods?										
Q3. Are characteristics of the patients included in the study clearly described?	1	1	1	1	1	1	1	1	1	1
Q4. Are the interventions clearly described?	1	1	1	1	1	1	1	1	1	1

Q5. Are the distributions of principal confounders in each group of subjects clearly described? 2,1,0	2	1	1	2	2	2	1	1	1	2
Q6. Are the main findings of the study clearly described?	1	1	1	1	1	1	1	1	1	1
Q7. Does the study estimate	1	1	1	1	1	1	0	1	1	1

random variability in data for main outcomes?										
Q8. Have all the important adverse events consequential to the intervention been reported?	0	0	0	0	0	0	0	0	0	0
Q9. Have characteristics of patients lost	1	1	1	1	1	1	1	1	1	1

to follow-up been described?										
Q10. Have actual probability values been reported for the main outcomes except where probability < 0.001?	1	1	1	1	1	1	1	0	1	1
Q11. Were subjects who	1	1	1	1	1	1	1	1	1	1

were asked to participate in the study representative of the entire population recruited?										
Q12. Were those subjects who were prepared to participate representative	0	1	1	0	1	1	1	0	0	1

of the recruited population?										
Q13. Were staff, places, and facilities where patients were treated representative of treatment most received?	1	1	1	1	1	1	1	1	1	1
Q14. Was an attempt made to blind study	0	0	1	0	0	0	0	1	NA	0

subjects to the intervention? Bias - in measurement of intervention and outcome.										
Q15. Was an attempt made to blind those measuring the main outcomes?	0	0	0	0	0	0	0	0	0	1
Q16. If any of the results of	1	1	1	1	1	1	1	1	1	1

the study were based on data dredging was this made clear?										
Q17. Was the time period between intervention and outcome the same for intervention and control	1	NA	1	1	1	1	1	1	NA	1

groups or adjusted for?										
Q18. Were the statistical tests used to assess main outcomes appropriate?	1	1	1	1	1	1	1	1	1	1
Q19. Was compliance with the interventions reliable?	1	1	1	1	1	1	1	1	1	1
Q20. Were main outcome	1	1	1	1	1	1	0	1	1	1

measures used accurate? (valid and reliable)										
Q21. Were patients in different intervention groups recruited from the same population?	1	NA	1	1	1	1	1	1	NA	1
Q22. Were study subjects in different	1	NA	1	1	1	1	1	1	NA	1

intervention groups recruited over the same period of time?										
Q23. Were study subjects randomized to intervention groups?	1	0	1	1	1	1	1	1	NA	1
Q24. Was the randomized intervention assignment	0.5	NA	1	0	0	0	0	0	NA	0

concealed from patients and staff until recruitment was complete?										
Q25. Was there adequate adjustment for confounding in the analyses from which main findings were drawn? Confounding	1	1	1	1	1	1	1	1	0	1

Q26. Were losses of patients to follow-up taken into account? Confounding	1	1	1	1	1	1	1	1	1	1
Q27. Was the study sufficiently powered to detect clinically important effects?	0.5	0	0.5	0.5	0.5	0.5	1	0	0	1
Total:	**22**	**17**	**23.5**	**21.5**	**23.5**	**23.5**	**21**	**21**	**16**	**24**

Out of:	**28**	**23**	**28**	**28**	**28**	**28**	**28**	**28**	**23**	**28**
Total percentage score:	**79%**	**74%**	**83%**	**77%**	**84%**	**84%**	**75%**	**75%**	**70%**	**86%**
Quality rating % (Hooper et al, 2008)	Good	Good	Good	Good	Good	Good	Good	Good	Good	Good
Quality rating by score	Good	Fair	Good	Good	Good	Good	Good	Good	Fair	Good

Quality rating: Excellent (93%+/26-28); good (71%+/20-25); fair (54%+/15-19); and poor (>53%/<14). (Hooper et al, 2008).

Note. Scoring for question 27 modified according to O'Connor et al. [x (, 2015]): 1 = power analysis conducted and study sufficiently powered, 0.5 = power analysis completed but not sufficiently powered; 0 = power analysis was not conducted / 'can't tell'. All items scored: 1 point = criterion was fully met; 0 = criterion was not met / 'can't tell'. N/A = question not applicable to study design.

Paper 2: Empirical Paper

Do psychological flexibility, self-compassion, spirituality, and time-since diagnosis predict mental wellbeing in UK adults living with a primary malignant brain tumour?

Word Count: 7985/8000

(Excluding title page, tables and figures: 390)

This paper is written for intended publication in Neuropsychological Rehabilitation, following submission guidelines (Appendix 13). There is format-free referencing in this journal thus APA 7th was selected. Further modifications will be made before submission.

Abstract

Primary Malignant Brain Tumours (PMBT) present significant and unique psychological challenges compared to secondary and non-cancerous brain tumours, with low survival rates, functional changes, and distress. Wellbeing, which encompasses emotional and functional health is related to improved experiences and outcomes in other cancer populations. Psychological flexibility, self-compassion, and spirituality have been found to support wellbeing in other cancer studies. A longer time-since diagnosis has also been associated with better wellbeing. Understanding whether these factors contribute to wellbeing in PMBT remains unexplored. The following hypothesis was tested and partially met in a cross-sectional multiple regression of 95 UK participants: Greater psychological flexibility, self-compassion, and spirituality, and time-since diagnosis predict better wellbeing, whilst controlling for age and gender. Psychological flexibility (β = .55, $p < .001$), spirituality (β = .26, $p = .004$), time-since diagnosis (β = .14, p = .01), and being male (β = .17, $p = .003$) were significant predictors. Self-compassion was significant when using the two-factor (self-kindness/self-criticism) scoring method (β = .24, $p = .006$) rather than the self-compassion mean. Psychological flexibility had the strongest effect. Improving psychological flexibility, spirituality, and self-compassion, closer to diagnosis, bearing gender differences in mind, might support wellbeing in PMBT.

Introduction

Background

Primary malignant brain tumours (PMBT)

PMBT are cancerous tumours originating in the brain, as opposed to brain tumours that are non-malignant or secondary malignancies metastasising from elsewhere in the body (Lapoint et al., 2018). Brain tumours (BT) differ in prognoses, treatment, and impact; thus, it is recommended to investigate malignant, non-malignant, primary, and secondary BT separately (Taphoorn et al., 2010). However, most research to-date includes participants with all BT types (Baker et al., 2016). As physical and functional impacts vary, the psychological experiences of living with a primary cancer of the brain are also likely to be unique. Patients with primary BT experience greater psychological symptoms than those with secondary (Ostgathe et al., 2009). People with malignant BT report higher distress than those with non-malignant (Fehrenbach et al., 2021). Understanding the factors that predict wellbeing in people with PMBT specifically is thus warranted to better support the psychological needs of this population.

PMBT classification, types and prevalence. BT were historically graded according to growth and malignancy (The Brain Tumour Charity, 2024). Grades 1-2 grow slowly and are less likely to spread; grades 3-4 are fast-growing malignancies with shorter prognoses (Komori, 2021). However, the current World Health Organisation classification emphasises molecular diagnostics over grading (WHOCNS5; Louis et al., 2021). For example, some grade 3 BT are considered lower-grade due to improved survival rates (van Den Bent et al., 2023).

Sixty-four percent of primary BT are malignant and occur in more males than females (1.64:1.00 ratio; Wanis et al., 2021). Most adult PMBT are gliomas (van Den Bent et al., 2023), named according to the glial cells in which it originated (The Brain Tumour Charity, 2024). Grade 4 astrocytomas, growing from astrocyte cells, are commonly referred to as glioblastomas (GBM) (The Brain Tumour Charity, 2024); although WHOCNS5 now only classify IDH-wildtype as GBM (Louis et al., 2021). GBM are the most malignant and pervasive gliomas (Li et al., 2023), accounting for the majority of PMBT in the UK (49%; Phillips, 2018). In England, GBM mostly occur in 65-74-year-olds (Wanis et al., 2021); however, worldwide, most occur in 40-64-year-olds (Li et al., 2018). Despite treatment advances, the median survival rate remains under 12 months (Weller, 2020; Wen et al., 2020), with six percent of patients living five years post-diagnosis (Ostrom et al., 2021). Whilst rare, the nineth most common cancer in the UK (Cancer Research UK, 2024), PMBT have the second-lowest survival rates (Nuffield Trust, 2024), remaining among the most difficult to treat (Lapoint et al., 2018). With a relatively young onset and short prognoses, it is understandable being diagnosed with PMBT is experienced as distressing and depressing (Goebel et al., 2010; Rooney et al., 2013).

PMBT impact

Ownsworth (2016) describes PMBT as a 'double threat': to one's survival, with potential poor prognoses; and to one's sense of self, with the significant accompanying physical and psychological changes. The wide-ranging symptoms associated with PMBT depend on the location, variant, and size (Louis et al., 2021; Trad et al., 2015). Physical and cognitive symptoms and treatment side-effects include pain, headaches, seizures, vomiting, sleep difficulties, visual

impairment, memory problems (Acquaye et al., 2019), motor deficits, and cognitive impairments (Chieffo et al., 2023). PMBT also causes behavioural and personality changes including disinhibition, apathy, reduced social awareness, and diminished empathy (Gregg et al., 2014). PMBT can also impact continence, mobility, communication, cognition, and ability to self-care, therefore likely impacting autonomy and independence (Dutta et al., 2009).

Quality of Life (QOL) is affected by these physical and cognitive impacts, as well as untreated psychological symptoms (Baker et al., 2016; Mathiesen et al., 2003). Thirty-three to forty-eight percent of PMBT patients experience mental ill-health (Gibson & Graber, 2020). Huang et al.'s (2017) systematic review calculated distress prevalence rates at 21.7% but this ranges from 16–41% due to variance in self-report tools (van den Meer, 2023). Compared to other cancers, anxiety is more prevalent in PMBT, at 21.5% (Zeilinger et al., 2022). Suicidality prevalence rates range from 21.5-33.3% compared to 0.03-6.00% in the general population (Mofatteh et al., 2023).

Psychological distress is associated with accelerated cancer progression (Lamba et al., 2018), worsened treatment outcomes (Gibson & Graber, 2020), and shortened survival (Noll et al., 2019). Likewise, poor QOL contributes to symptom burden, functional decline (Armstrong et al., 2013), and diminished health outcomes (Baker et al., 2016). However, not everyone living with cancer experiences distress and worsened QOL (Ciarrochi et al., 2011). Exploring what mitigates the potential challenges to wellbeing in PMBT is thus pertinent, to improve both physical and mental health.

Mental and physical health and QOL are closely intertwined, impacting each other multi-directionally (Tennant et al., 2007). These interdependent domains can be captured by the concept 'wellbeing'. The present study will capture the psychological and functional aspects of PMBT by measuring wellbeing.

Wellbeing

Defined as 'feeling good and functioning well' (Tennant et al., 2007) wellbeing includes emotional, physical, and social aspects of health. Historically, wellbeing has been measured through items related to one of these aspects (Stewart-Brown et al., 2009; Ruggeri et al., 2020). However, validated tools now exist to encompass the multi-faceted properties of wellbeing (e.g., Tennant et al., 2007). Psychological flexibility, self-compassion, spirituality, and time-since diagnosis have been found in other cancer studies to influence wellbeing.

Psychological flexibility (PF)

Doing things deemed important to an individual, known as valued-living (Wilson et al., 2010), significantly predicts better wellbeing and less distress for cancer patients (Ciarrochi et al., 2011). Psychological flexibility (PF) involves being present with and opening-up to difficult experiences whilst engaging with valued-living (Hayes et al., 2006). Higher PF is associated with lower distress in cancer studies (Fawson et al., 2023). PF predicted lower depression and anxiety in breast cancer patients (Montiel et al., 2016), higher QOL in prostate cancer patients (Sevier-Guy et al., 2021), and decreased mental distress for young people (11 - 24-year-olds) with PMBT (Airdrie, 2022). Conversely, psychological inflexibility (PI) is responding rigidly to, or avoiding, difficult thoughts and feelings, interfering with valued-living (Hayes et al., 2012). It is

associated with worse wellbeing in adults (Ong et al., 2024), pain in cancer patients (Brown et al., 2020), and worse QOL in breast cancer patients (Novakov, 2020). Recent research has thus investigated interventions improving PF to minimise the impact of cancer symptoms (Mosher et al., 2021).

Acceptance and Commitment Therapy (ACT) provides strategies to improve PF and engage with valued-living (Hulbert-Williams et al., 2015). Fang et al.'s (2022) systematic review of ACT interventions for advanced cancer found the interventions which improved mood and QOL were those supporting participants to reduce focus on symptoms by normalising distress, living in the moment, and increasing social and physical activities. None of these studies, however, included adults with PMBT. A large randomised controlled trial found ACT maintained or improved QOL in people with motor neurone disease, a progressive and fatal neurodegenerative condition, highlighting the potential benefit of ACT for PMBT (Gould et al., 2024). Only one study to the author's knowledge has explored ACT exclusively in PMBT (Kangas et al., 2015). This study reported improvements in depression and anxiety, but as a single-case experimental design it is difficult to generalise findings (Morley, 2017). The role of PF in PMBT remains relatively unexplored, yet important to consider when supporting wellbeing in PMBT.

Self-compassion

Self-compassion comprises three processes: awareness of distress and suffering (mindfulness), understanding suffering is part of life (common humanity), and offering kindness to oneself for difficulties (self-kindness) (Neff, 2003). Cancer patients with high self-compassion report better psychological outcomes, with older participants reporting higher self-compassion

and females lower (Wei et al., 2022). Higher self-compassion significantly predicted lower depression and stress and increased QOL in a mixed cancer sample (Pinto-Gouveia et al., 2013). Fawson et al.'s (2023) meta-analysis of 108 cancer studies found lower self-compassion was associated with higher psychological distress. L'Estrange et al. (2016) found actively learning and practising self-compassion was perceived by cancer patients to improve wellbeing. Self-compassion interventions include Compassion-Focussed Therapy (Gilbert, 2009) and Mindful Self- Compassion (Germer & Neff, 2019).

However, none of these studies included PMBT participants, or excluded those with brain injury or cognitive impairment likely eliminating those with PMBT. Fostering PF and self-compassion might be useful for people with PMBT given their uncertain prognoses, impairments, and well-documented distress (Kangas et al., 2015).

Spirituality

In a qualitative study, participants reported having a spiritual connection mitigated the psychological burden of PMBT (Zahid Shah et al., 2023). A patient consulted for this study expressed how important spiritual connection was for their wellbeing given the uncertainty of PMBT. In a systematic review of definitions, de Brito Sena et al. (2021) recognise spirituality is a broad and complex concept, with definitions varying and open to interpretation. They concluded spirituality is a 'personal connection with something that promotes meaning and personal growth'. Spirituality is particularly pertinent for PMBT patients as they face significant life changes as well as existential crises due to poor prognoses (Watanabe & MacLeod, 2005). In other cancer populations, discovering meaning in hardship protects against anxiety and

depression (Gustavsson-Lilius et al., 2006), and spirituality predicts higher wellbeing (Hunter-hernández et al., 2015).

Studies have found connections between spirituality and mental health or QOL in people with primary BT (malignant and non-malignant). Pelletier et al. (2002) found a relationship between depression, fatigue, emotional distress, and existential crises. Randazzo and colleagues (2021) found higher rates of reported spirituality were predictive of improved QOL. Baksi et al. (2021) found participants with primary BT had lower psychological hardiness (resistance to stress) compared to healthy controls, and spirituality predicted hardiness. The former used a correlational analysis thus prediction was not determined. Whilst the latter two employed multiple regression analyses, the constructs predicted were not wellbeing, which encompasses mental health and QOL, both impacted by PMBT. Psychological interventions supporting patient spirituality by finding meaning and purpose include the Making Sense of Brain Tumour programmes (MAST; Jones et al., 2015; Ownsworth et al., 2022; Ownsworth et al., 2023), Managing Cancer and Living Meaningfully programme (CALM; Loughan et al., 2022), dignity therapy (Julião et al., 2014), reminiscence therapy (Zhao, 2021), and meditation (Milbury et al., 2020). All report positive effects on depression, anxiety, and existential wellbeing. As none of these spirituality studies examined exclusively PMBT participants, there remains scope to explore the predictive value of spirituality on wellbeing in a PMBT sample.

Time-since diagnosis

In patients treated for GBM, Palmer et al. (2021) found those reporting a greater time-since diagnosis also reported better QOL. They speculated these results could have been

influenced by treatment effects or the impact of cognitive decline on reporting QOL. Whilst cognitive decline can lead to inaccurate self-reports (Akpınar Söylemez et al., 2020), it does not always (Trigg et al., 2007) and is more often associated with reports of poorer wellbeing (Stites et al., 2017). Thus, another cause or mechanism may be influencing the relationship between time-since diagnosis and wellbeing.

Improved wellbeing over time was also found in a large-scale American cancer study (Sullivan et al., 2017); however, reasons were not explored. The wealth of oncology literature on adjustment (e.g. Brenan, 2004) may offer some explanation. Many factors are hypothesised to influence adjusting positively to living with cancer, including coping styles (Johansson et al., 2011), outlook (Iseki, 2023), and finding benefit or meaning in the experience (Carver & Antoni, 2004; Schroevers et al., 2006).

The current study will extend Palmer's findings to a wider PMBT sample. Although it will not be possible to identify what underpins this relationship, investigating the predictive value of time on wellbeing could prove useful for highlighting when wellbeing challenges peak and thus when intervening would be useful.

Age and gender

Age and gender have been associated with differences and similarities in cancer outcomes, coping styles, and GBM presentation (e.g., Colopi et al., 2023; Martins-Klein et al., 2019; Tian et al., 2018; Wei et al., 2023; Zhou et al., 2023), thus, they will be controlled for. Due to conflicting evidence, a directional hypothesis was deemed unfounded.

Rationale

The psychological toll of living with PMBT is well-documented, with patients reporting high levels of depression, anxiety, suicidality, and low QOL (Baker et al., 2016; Cubis et al., 2019; Lidstone et al., 2003; Mofatteh et al., 2023). Improving psychological outcomes can impact treatment adherence and therefore efficacy (Khalili et al., 2021). Psychological flexibility, self-compassion, and spirituality have been found in other cancer populations to predict, improve, or mitigate adverse, psychological experiences (Airdrie, 2022; Hunter-Hernández et al., 2015; Montiel et al., 2016; Sevier-Guy et al., 2021). A longer time-since diagnosis predicts QOL in GBM (Palmer et al., 2021). Participants with PMBT are underrepresented in cancer studies (e.g. Fang et al., 2022). When these constructs have been explored in BT populations, samples often combine primary, secondary, malignant, and non-malignant BT. This is not recommended due to BT heterogeneity and the unique experiences of PMBT specifically (Baker et al., 2016).

The underrepresentation of PMBT participants in research to-date is in part due to cognitive impairment being an exclusion criterion (L'Estrange et al., 2016). With both perceived and actual cognitive impairments accompanying PMBT and its treatments (Nicol et al., 2019), patients are excluded by nature of the disease. Recent research into PF, spirituality, and self-compassion in populations experiencing cognitive impairment including older adults (Hall & Beatty, 2014), dementia (e.g. Craig et al., 2018), brain injury (e.g. Ambridge et al., 2020), and motor neurone disease (e.g. Gould et al., 2024) demonstrates it is possible and fruitful to explore these constructs in PMBT where cognitive impairment is possible. Whilst cognitive impairment may impact wellbeing in PMBT (Nicol et al., 2019), the present study did not

measure it for a number of reasons. It is potentially inherent to PMBT, would be burdensome to complete measures on it, and cognitive ability was assumed by self-selecting participation.

Aims, objectives and hypotheses

The aim of this study was to investigate whether PF, self-compassion, spirituality, and time-since diagnosis predict wellbeing in participants with PMBT whilst controlling for age and gender. The following hypothesis was tested through multiple regression analysis: A longer time-since diagnosis and higher levels of PF, self-compassion, and spirituality will predict higher wellbeing.

It is hoped the results contribute to understanding the constructs of PF, self-compassion, spirituality, and the multi-faceted construct of 'wellbeing' in an under-researched population to inform the design of psychological interventions aiming to reduce the emotional impact of PMBT.

Method

Design

Cross-sectional quantitative studies provide a 'snapshot' of differences in an outcome across people and phenomena (Lavrakas, 2009). Participants were recruited via charities and social media for this cross-sectional quantitative study exploring the relationship between time-since diagnosis, PF, self-compassion, spirituality, and wellbeing. Purposive and convenience sampling meant these phenomena within the population of adults living with PMBT will be investigated. The study received ethical approval from Staffordshire University Ethics

Committee (Appendix 1). All participants gave informed consent through the consent section at the start of the questionnaire.

Setting

Recruitment ran between January and December 2024. Brain tumour and cancer charities advertised the study through social media, email lists, and newsletters using the researcher's ethically approved advert, video, and text (Appendix 2). Some also posted in their private online groups for patients and carers which would not have been appropriate for the researcher to join solely to advertise the study. The researcher attended an in-person brain tumour support group run by a charity to verbally explain the study and leave posters (Appendix 3). The researcher created professional social media profiles on LinkedIn, Instagram, X, and Facebook, advertising the study on these platforms, 'tagging' charities, organisations, and individuals with relevant hashtags to reach wider audiences. Participants were invited to share the study too. Some health-care professionals put posters in waiting rooms, as this is not considered NHS research activity and thus within ethically approved activities (IRAS, 2025). Promotional material informed participants they could request paper questionnaires with pre-paid envelopes; however, none did.

Questionnaire

Participants accessed the study, hosted on Qualtrics (www.qualtrics.com), using a URL link in the adverts. The first page was the information sheet detailing the study, consent, withdrawal, and how data would be anonymised (Appendix 4). The subsequent page was the consent form (Appendix 5). Participants could not proceed without completing this. Participants

created a unique participant code using two letters and four numbers chosen at random by them. They were encouraged to record this should they wish to withdraw. Participants then completed the demographic questions capturing time-since diagnosis (Appendix 6) and four pre-existing measures. A debrief sheet was displayed upon submitting the questionnaire (Appendix 7). Advertisements stated the questionnaire was estimated to take 15 minutes to complete and could be started then completed within two weeks if using the same device.

Participants

To be eligible, participants needed to be over 18, living with PMBT in the UK, and able to understand English (due to lack of financial resources for translated questionnaires and translators). People outside the UK were excluded as diagnosis and treatment processes and services vary between countries, making conclusions and recommendations difficult. People with a non-malignant or secondary BT were excluded due to the aforementioned differences in experiences (Baker et al. 2016). However, as diagnosis was self-reported, the researcher was not able to objectively verify this. Acknowledging the potential cognitive impairment experienced by this population and previous exclusion from studies due to this, cognitive impairment was not an exclusion criterion. Participants were eligible if they felt able to read and answer the questionnaires. Participants were invited to gain support to complete the questionnaire, as long as it was their personal opinion recorded, not their supporter's. Incomplete questionnaires were classed as withdrawals and excluded. Participants could leave contact details to receive a summary of findings.

As a non-funded project, gratitude for participation was not expressed through financial means but through a written thank you in the debrief sheet (Appendix 7). One charity showed considerable support for the project, thus the researcher facilitated a wellbeing webinar for their beneficiaries in return.

Ninety-five people participated in the study through the online Qualtrics link. Six-hundred and eighty-three incomplete surveys were removed following ethics procedures where withdrawn consent was assumed by incomplete surveys. These Fifty-seven percent identified as female, 40% as male, 1% as non-binary, and 2% did not want to disclose their gender. Incidence of GBM is higher in people assigned male sex at birth (Colopi et al., 2023). Notably, this is a biological sex, not gender, difference. The representativeness of the current sample is thus hard to determine as the current study collected gender data and incidence rates usually use sex data (Kaufman, Eshcilmann & Karver, 2023). The higher rates of female respondents reflect previously reported over-representation of women participating in online, cross-sectional studies (Becker, 2022). Age ranged from 24-78 years with two modes of 37 and 53 years. This is reflective of research reporting malignant BT occurring more in the 41-60 age-bracket (Shaff & Mellinghoff, 2023). Time-since diagnosis ranged from 0–264 months (22 years) with most reporting 30-33 months since diagnosis (2.5 years). Most of the sample (40%) reported a diagnosis of GBM. Four of the 'other' diagnoses (Grade 2 Astrocytoma, Choroid plexus, Central Neurocytoma, and Vestibular schwannoma) are usually non-malignant (Park et al., 2012; Tadros et al., 2021). However, diagnoses are complex and can change over time. The purpose of this

question was not to screen participants thus it is assumed those who participated felt they met eligibility criteria.

Table 1: Sample characteristics (N = 95).

Demographic characteristic	***n* (%)**	**Mean (SD)**	**Range**
Age (years)	NA	(*M* = 49.7; *SD* = 11.8)	24-78
Gender			
Female	54 (56.8%)		
Male	38 (40%)		
Non-binary	1 (1.1%)		
Not-disclosed	2 (2.1%)		
Tumour type			
Glioblastoma	40 (42.1)		
Astrocytoma	18 (18.9)		
Anaplastic astrocytoma	16 (16.8)		
Anaplastic oligodendroglioma	7 (7.4)		
Meningioma	3 (3.2)		
Don't Know	3 (3.2)		
Other	8 (8.4)		
-Acoustic neuroma	1 (1)		
- Central Neurocytoma	1 (1)		
- Choroid plexus	1 (1)		
- Grade 2 Astrocytoma	1 (1)		
- Myxoid Chondrosarcoma	1 (1)		
- Oligodendroglioma	1 (1)		
- Vestibular schwannoma	1 (1)		
Time since diagnosis (months)		M = 42.9; SD = 51.4	0–264

Measurements

Demographic Information

Demographic information was collected using a questionnaire designed by the researcher (Appendix 6). Questions included participant age, gender, tumour type, and time-since diagnosis, to enable sample description, comparison across similar studies and as

variables (time-since diagnosis; gender). A dummy gender variable was created from this information: 'Male' responses were compared to 'female', 'non-binary' and 'not-disclosed' combined.

Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) (Tennant et al., 2007)

WEMWBS is a self-report 14-item scale measuring mental wellbeing. Sample items include 'I've been feeling relaxed' and 'I've been feeling close to other people', which participants rate on a 5-point Likert scale from 1 ('none of the time') to 5 ('all of the time') in regard to the preceding two weeks. Scores can be divided into high, average, and low mental wellbeing with the top 15% of scores (60 - 70) indicating high and the bottom 15% (14-42) indicating low wellbeing (Tennant et al., 2007). Considering the potential burden of completing numerous measures, the WEMWBS was selected over individual measures of distress and QOL. Whilst this tool has not been used to the researcher's knowledge in PMBT populations, it was selected because it considers functional and emotional aspects of health, encompassing concepts of anxiety, depression, and QOL. It has been shown to be reliable and valid in general (Cronbach's α = 0.91; Tennant et al., 2007), cancer (Cronbach's α = 0.87; Shaheed et al., 2019), and secondary care populations (Cronbach's α = 0.95; Bass et al., 2016), with high test-retest reliability (r = 0.83; Tennant et al., 2007).

Multidimensional Psychological Flexibility Inventory-24 (MPFI24) (Rolffs, Rogge & Wilson, 2016).

The MPFI-24 is a 24-item scale measuring psychological flexibility. It comprises a 6-point Likert scale where respondents rate how often in the past two weeks they, for example, 'tried

to make peace with negative thoughts and feelings rather than resisting them' or 'let negative feelings come and go without getting caught up in them'. It produces two scores: PF and PI. There are no cut-offs; rather, higher scores reflect higher PF or PI (Sundström et al., 2022). Averages of the PF and PI subscales are averaged to create a global PF and PI score with a maximum of 6 on each. It has adequate internal consistency (Cronbach's α = 0.83; Grégoire et al., 2020). The MPFI-24 has been found to have validity in terms of linking to wellbeing and psychological distress (Rolffs, Rogge & Wilson, 2016). No studies to the researcher's knowledge have used this scale in PMBT. However, it was selected as it has been shown to have good convergent validity and excellent internal consistency reliability in other conditions including chronic pain, with Cronbach's alphas ranging from .81 to .96 (Sundström et al., 2022).

Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-Sp-12) (Peterman et al., 2002)

FACIT-Sp-12 is a 12-item scale measuring spiritual wellbeing of those living with chronic illness (Peterman et al., 2002). Questions include, 'I feel a sense of purpose in my life' and 'I know that whatever happens with my illness, things will be okay' with a 5-point Likert scale response ranging from 0, ('not at all'), to 4, ('very much'). Total scores range from 0-48. With no cut-offs, higher scores reflect higher spiritual wellbeing (Peterman et al., 2002). 'High' spiritual well-being has since been proposed as a ≥36 and 'low' as <36 (McClain et al., 2003). It is the most widely used measure of spiritual wellbeing in cancer (Munoz et al., 2015). Reliability is good (Cronbach's α = .81–.88) and validity moderate to strong (Peterman et al., 2002). It has good reliability and validity in ethnically diverse samples and across a range of religious

traditions, including respondents who describe themselves as spiritual but not religious (Munoz et al., 2015). In an American cancer population, reliability was found to be acceptable (Cronbach's α = .70; Munoz et al., 2015). Only three items refer explicitly to 'faith or spiritual beliefs', thus it was deemed appropriate for measuring spirituality according to the definition in this study (deBrito Sena et al., 2021).

Self-compassion scale short-form (SCS-SF) (Raes et al., 2011)

The SCS-SF is a 12-item self-report measure with a 5-point Likert scale ranging from 1 ('almost never') to 5 ('almost always') measuring the three components of self-compassion (mindfulness, common humanity, self-kindness). Sample items include 'When I'm going through a very hard time, I give myself the caring and tenderness I need' and 'When I'm feeling down, I tend to obsess and fixate on everything that's wrong'. An overall mean self-compassion score is calculated ranging from 0-5. With no clinical norms or cut-offs, Neff et al. (2019) suggest higher overall scores indicate higher self-compassion with scores of 1-2.5 indicating 'low' self-compassion, 2.5-3.5 'moderate', and 3.5-5 'high'. This approach is different to the original scoring (Raes et al., 2011). However, Neff et al., (2019) recommend it to ease interpretation and report most researchers to be using this recent approach. It has adequate internal consistency (Cronbach's $\alpha \geq 0.86$), and near perfect correlation ($r \geq 0.97$ all samples) to the original long-form SCS (Raes et al., 2011). Other self-compassion scales exist (e.g., The Compassionate Engagement and Action Scale, Gilbert et al., 2017); however, the SCS and SCS-SF are the ones most used in cancer populations (Badaghi et al., 2024).

Statistical methods

Data screening

Data were screened and cleaned prior to analysis to enhance data quality and validity. Responses were excluded if they were incomplete (as per ethics; Appendix 1), completed implausibly quickly (suggesting automated or inattentive responding), or extreme (e.g. consistently maximum or minimum scores).

Data analysis

Data were analysed in IBM SPSS Statistics (Version 28). Multiple regression was used to assess how the constructs uniquely and collectively predicted wellbeing, accounting for shared variance (Field, 2018). An independent statistician (WM) reviewed the analysis and interpretation.

Power analysis

For a multiple regression based on a similar study (Marton & Vizin, 2023) with six predictor variables, one criterion variable (wellbeing), a medium effect size (0.15), power set to 0.8 and alpha at 0.05, it was calculated 84 participants were required (Soper, 2023). Recruitment stopped when this number was surpassed. However, the MPFI-24 produced two variables (PF and PI), thus 103 participants would be required (Soper, 2025). This means the model was underpowered, leaving a chance of type II errors.

Multiple regression model assumptions and diagnostics

Appendix 8 shows the normal distribution of the dependent variable, wellbeing. Model assumption test outputs are in Appendices 9 and 10. Distributions of independent variables were not deemed to violate assumptions of the model. Scatterplots of predictor variables against wellbeing revealed linear trends (Appendix 9.3). The Shapiro-Wilk test confirmed the residuals' normality (W = .981, p = .198). Variance Inflation Factor (VIF) scores were below 4 for all predictors, indicating no multicollinearity concerns (Appendix 10). Analysis of residuals showing random dispersion confirmed the model's adherence to the assumptions of homoscedasticity and linearity for multiple linear regression (Appendix 10). These tests indicate the key assumptions of the multiple linear regression model were achieved thus the subsequent analysis was completed.

Results

Descriptive statistics of variables

The mean, standard deviation and range for scores on the measures of wellbeing, PF, self-compassion, and spirituality are presented in Table 2. Age, gender, and time-since diagnosis were presented in Table 1. Appendix 8 contains full scores and data. Cut-offs are not reported as none of the measures had them. Skewness and kurtosis scores indicate the data were symmetrical and normally distributed enough not to violate assumptions.

Table 2: Descriptive statistics for predictor variables

	M	**Median**	***SD***	**Skewness; Kurtosis**	**Range (min. – max.)**	**Theoretical range**

						(min. – max.)
Wellbeing (WEMWBS)	45.9	46	10.6	-.169; .200	14-70	14-70
Self-Compassion (SCSSF)	3	3	0.8	.195; -.510	1.5-4.75	1-5
PF (MPFI-24)	3.8	3.8	0.9	-.020; -.027	1.1-6	1-6
PI (MPFI-24)	3.1	3	0.8	.124; -.243	1-5.2	1-6
Spirituality (FACIT-Sp-12)	25.2	24	11	.300; -.606	4-48	0-48

Without cut-offs, scores can be interpreted against each measure's theoretical range and other cancer studies. Against the measures' range, the sample reported moderately on all scales; meaning there was some presence of the measured construct, but none yielded particularly high or low scores.

The sample's mean wellbeing of 45.7 can be categorised as 'average'; slightly lower than the UK general population mean (51; Tennant et al., 2007). Most researchers interpret results against this (Warwick Medical School, 2021). However, Moschopoulou et al. (2021) reported the median of a head and neck cancer sample as 53; higher than the current sample's median of 46.

The mean of the sample's self-compassion score would be considered 'moderate' (Neff, 2019). A total mean (36) was calculated to facilitate comparison. This is comparable to the general population (Raes et al., 2011), lower than a Brazilian oncology population with a mean average score of 4.23 ('high' self-compassion) (Garcia et al., 2021) but higher than a UK breast cancer sample (28.4 total mean before a self-compassion intervention, 42.1 post-intervention; Hoffman & Baker, 2023).

The sample mean PF and PI scores were just above 3 which is the midpoint on the scale, indicating moderate PF and PI. These are lower than a non-clinical Spanish sample where both scores were 4 (Barado-Mareno et al., 2025). The author could not find cancer populations that used this measure for comparison, and the chronic pain studies did not report composite means (Sundström et al., 2022; Lavefjord et al., 2025).

The mean spirituality score fell exactly halfway between the scale's range. However, previous studies have classified this as 'low' (McClain, Rosenfelt & Breitbart, 2003; Monod et al., 2015). It is comparable to a UK study in non-illness populations with mean 25.9 for non-religious and 30.2 for religious participants (Whitehead et al., 2022), perhaps reflecting the current sample were not religious. However, a French study of older adults in a rehabilitation hospital reported a higher mean of 29.6 (Agli, Bailly & Ferrand, 2016).

These relatively and comparatively moderate-low scores may reflect the distress, disability and existential crises caused by PMBT (Ownsworth, 2016), or the study may have appealed to those struggling more and wanting to contribute to research on this topic.

Correlations

To understand the relationship between the constructs measured and support the regression analysis, Table 3 presents a correlation matrix.

Table 3 Pearson's r correlations for study variables (n = 95).

Variable	1	2	3	4	5	6	7
1. Wellbeing (WEMWBS)	-						

2. Age (Years)	.242**	-					
3. Time-since diagnosis (Months)	.094	-.027	-				
4. Self-compassion (SCSSF)	.662***	.290**	-.065	-			
5. PF (MPFI-24)	.807***	.272**	-.049	.676***	-		
6. PI (MPFI-24)	-.513***	-.147	.057	-.711***	-.515***	-	
7. Spirituality (FACIT-Sp-12)	.740***	.235*	.078	.645***	.752***	-.454***	-
8. Gender (Male / Not Male)	.029	.106	-.192*	-.008	-.130	-.046	-169

Note. *$p < .05$; **$p < .01$; ***$p < .001$.

The outcome variable, wellbeing, was significantly correlated with five of the independent variables: age, self-compassion, PF, PI (negative), and spirituality.

A weak but significant positive correlation was found between age and wellbeing, with an increase in years associated with higher wellbeing scores. Strong, significant positive correlations were found between wellbeing and self-compassion, PF, and spirituality, suggesting as self-compassion, PF, and spirituality increased, wellbeing also increased. Strong, significant negative correlations with PI and wellbeing suggest as PI decreased, wellbeing decreased.

Some independent variables were significantly correlated with each other (all correlations with PI were negative). Weak but significant correlations were found between age and self-compassion, PF, and spirituality, suggesting increases in these variables were

associated with increases in age. A weak correlation between time-since diagnosis and gender suggests an increase in months since diagnosis was associated with being male (as 1 was male in the dummy variable). Strong, significant correlations were found between self-compassion and PI, PF, and spirituality, indicating an increase in self-compassion scores was associated with an increase in PF and spiritually and a decrease in PI scores. Strong, significant correlations were found between PF and PI and spirituality, suggesting as PF scores increased, spirituality scores increased, and PI scores decreased. A moderate, significant, negative correlation was found between PI and spirituality, suggesting as PI scores decreased, spirituality scores increased.

Multiple Regression Analysis

A multiple regression analysis was conducted to test the hypothesis that higher levels of PF, self-compassion, and spirituality, and a longer time-since diagnosis will predict higher wellbeing whilst controlling for age and gender. Predictor variables (both MPFI-24 PF and PI scores, self-compassion, spirituality, months-since diagnosis, age, and gender) and the criterion (wellbeing) were entered into the model at the same time (Table 4; Appendix 10).

Model fit

The overall fit of the model was significant (F (7, 87) = 36.06, p < .001), suggesting the model explains a significant portion of variance in wellbeing scores in this sample. The model accounts for approximately 72% of variance in wellbeing, with an adjusted R^2 of 0.72, highlighting a substantial impact of the included predictors. This is a large effect size (R^2 > 0.25; f^2 > 0.25; Emerson, 2023).

Table 4: Multiple-regression results

	B	*SE B*	*β*	Sig.	95% CI	
					Lower	Upper
Constant	10.89	6.30		.087	-1.63	23.41
Age (years)	-0.20	0.05	-.022	.701	-0.12	0.08
Time since diagnosis (months)	0.03	0.01	.143	.013	0.01	0.05
Self-compassion (SCSSF - mean)	1.52	1.25	.116	.226	-0.96	4.01
Flexibility (MPFI)	6.28	1.03	.554	<.001	4.24	8.33
Inflexibility (MPFI)	-0.42	1.02	-.32	.679	-2.45	1.60
Spirituality (FacitSp)	0.25	0.09	.257	.004	0.08	0.42
Gender (Male / Not-male)	3.74	1.23	.174	.003	1.29	6.19

Coefficients and Confidence Intervals

The intercept, β_o, was estimated at 10.89 points, the average wellbeing score when all independent variables are zero. Psychological flexibility was significantly associated with an increase in wellbeing by 6.28 points and was the most significant predictor in the model. Being male significantly contributed an additional 3.74 points to wellbeing scores. An increase in spiritualty increased wellbeing significantly by 0.25. Each month since diagnosis significantly increased wellbeing by 0.03 points. PF had the strongest effect, followed by gender.

Discussion

This study examined whether greater PF, self-compassion, spirituality, and time-since diagnosis predict wellbeing in participants with PMBT whilst controlling for age and gender. A

multiple regression analysis showed this hypothesis was partially supported. The correlations and multiple regression results are discussed.

Correlations

The correlation results provide confidence in the measurements used and analysis conducted, as constructs were associated with each other and supported by previous data. Self-compassion, PF, and spirituality were highly associated with wellbeing, adding to the understanding of wellbeing as a multi-faceted construct (Ruggeri, Garcia-Garzon, & Maguire, 2020). This corresponds with existing research on positive relationships between wellbeing and self-compassion (MacBeth & Gumley, 2012; Zessin, Dickhäuser & Garbader 2015; Zhu et al., 2019), PF (Paiva et al., 2024; Proctor, Reiman & Best, 2023), and spirituality (MacCain, 2003; Ryaff, 2021).

Interesting correlations between variables were also observed. PF was associated with PI, adding to the understanding of this construct as containing both processes (Barrado-Moreno et al., 2025; Lavefjord et al., 2025; Navarrette et al., 2024; Rolffs, Rogg & Wilson, 2016). Higher PI was associated with lower spirituality, echoing previous studies (Marshall & Brockman, 2016; Mathad, Rajesh, & Pradhan, 2017). Correlations between age and PF, self-compassion, and spirituality have been found previously (Dominguez, Veronese, & Barbagallo, 2024; Hwang et al., 2016; Sundström et al., 2022) suggesting these constructs improve with age. Self-compassion was associated with higher PF and spirituality, and lower PI, highlighting its role in the processes of PF and spirituality. The correlation between time-since diagnosis and gender

meant males were reporting a greater time-since diagnosis which has previously been associated with better QOL (Palmer et al., 2021).

The regression analysis deepens these findings by specifying predictors and thus which factors are important to address when aiming to improve wellbeing.

Multiple regression

Psychological flexibility, spirituality, and time-since diagnosis were significant predictors of wellbeing. Self-compassion and PI were not. The covariates of age did not affect wellbeing scores, but being male significantly did. Thus, the hypothesis that a longer time-since diagnosis and higher PF, self-compassion, and spirituality will predict higher wellbeing whilst controlling for age and gender was partially supported.

Psychological flexibility was the strongest predictor, adding to findings from other cancer populations of its importance in supporting wellbeing (e.g. Procter, Reiman & Best, 2023) over other psychological factors (Sevier-Guy et al., 2021). Being male was the second strongest predictor. Male scores on the dependent variable were 3.74 points higher than non-males accounting for other variables. Whilst a directional effect of gender was not hypothesised, it was included as a covariate, and it had a significant effect. The gender differences in this study echo those reported in most studies in Zhou et al.'s (2023) systematic review. However, some reported no difference and others found worse psychological outcomes yet less support-seeking for males, making them a vulnerable group. The current results may reflect differences in coping styles, potentially indicating men cope better with cancer, previously found to be due to their problem-oriented coping (Vidhubala et al., 2006). However,

more recent research does not support this, with more positive coping styles found among females (Zhou et al., 2023). The gender difference in this study may reflect historical findings that men underreport mental health symptoms and overreport wellbeing due to stigma and perceived social expectations (Chatman, 2020). The correlation results might help explain why gender predicted wellbeing in this sample. Males in the sample were reporting a longer time-since diagnosis, which has previously been predictive of QOL (Palmer et al., 2021), thus males were reporting a longer time-since diagnosis and better wellbeing.

As hypothesised, higher spirituality and a longer time-since diagnosis significantly predicted wellbeing. This adds to research on spirituality in other cancer (Hunter-Hernández, Costas-Muñíz, & Gany, 2015) and BT populations (Baksi, Arda Sürücü & Genç, 2021; Pelletier et al., 2002; Randazzo et al., 2021). The predictive nature of time-since diagnosis echoes Palmer et al.'s (2021) findings in GBM.

Regression models are sometimes re-run with only significant variables. This one was not. Including non-significant variables provides comparative insights to how the hypothesised constructs feature in wellbeing (Field, 2018). Age did not influence wellbeing significantly, which means the current findings hold regardless of age. Self-compassion was not initially a significant predictor as hypothesised. This confirms the rationale for conducting a multiple regression, as the correlations imply self-compassion and wellbeing are related but not the predictive nature of this relationship. Compared to other variables (PF, gender, and spirituality) self-compassion was not as important to wellbeing in PMBT, which does not align with research in other cancer populations (Wei et al., 2022). As self-compassion forms part of PF (Neff &

Tirch, 2013), it might have been captured within that measure, supported by the high correlation between these constructs. However, the SCS-SF mean scoring approach is not without criticism (Muris et al., 2021; Muris & Petrocchi, 2016). In a UK sample, Kotera & Sheffield (2020) recommend interpreting SCS-SF with two-factors (self-compassion and self-criticism) rather than the mean. The regression was re-run with this scoring and the self-compassion factor was the fourth most significant predictor (Appendix 12). Self-criticism was not significant. This model was significant (F (7, 87) = 36.06, p < .001), and predicted 73% of the variance; 1% more than the original. However, running the regression in this way adds a variable, further affecting the power analysis. Whilst Neff holds the mean scoring remains valid (Neff, 2020), when consulted for the current study, Neff advised either scoring could be used (Appendix 14). Thus, it can be concluded with support of previous research that self-compassion plays a role in wellbeing in PMBT.

Whilst only PF, not PI, was hypothesised as a predictor of wellbeing, it could be assumed PI would negatively affect wellbeing. However, regression results revealed PI was not a significant predictor. Whilst this is contrary to existing research (Ong, Barthell & Hoffman, 2023), it adds to the understanding of PF and PI as related but not opposite constructs (Rolffs, Rogg & Wilson, 2016). As the initial hypothesis was related to PF not PI, there could be a rationale to remove PI from the model. This did not change the fit or significance of the model (Appendix 12) and the initial power calculation would stand, minimising type II errors.

Limitations

Whilst the current study highlights factors predicting wellbeing in an under-researched population, there are limitations to consider.

The ratio of male to non-male participants is roughly equal but does not match prevalence data. Perhaps because self-identified gender was collected rather than biological sex, which are different. Sex refers to biological sex assigned at birth based on anatomy; gender is an internal sense of being male, female and variations beyond the binary (ONS, 2023). However, sex is the more accurately understood variable which can affect disease expression and physical impact (Ozawa et al., 2019; Toledo et al., 2017), whereas gender identity relates to inequitable gender norms, roles, and policies (Kaufman, Eshcilmann & Karver, 2023). Thus, conclusions about the current findings must be taken with this distinction in mind.

Whilst efforts were made to recruit participants 'off-line' through in-person charity groups and offering paper questionnaires, all participants were online. This does not represent those who cannot access the internet. Whilst the limitations of a self-selecting sample were acknowledged, it must be noted that verification of participant eligibility (PMBT diagnosis; 18+; living in the UK) was not possible, and assurances that results apply to the target population cannot be made. However, without an incentive to participate it is unlikely those not meeting criteria would partake. The self-selecting nature of the sample also means the impact of potential cognitive impairment is unknown, which can influence accuracy in self-reporting (Akpınar Söylemez et al., 2020).

Data collection ceased when responses surpassed the original power calculation of 84. However, with the MPF-24 producing two variables the model was underpowered, thus type II errors are a possibility. Moreover, more participants would be needed if SCS-SF two-composite scores are used (Soper, 2025).

Cross-sectional regression studies provide a snapshot of variables at a single timepoint. Whilst cost-effective and useful for identifying predictive associations, they have limitations (Wang & Cheng, 2020). They do not highlight causation, for example. As such, it cannot be determined whether PF, self-compassion, and spirituality cause better wellbeing or vice versa. Randazzo et al., (2021) also noted in their cross-sectional study, there is no way of knowing how spirituality changes over time, which can be argued for the other constructs in this study. Whilst the regression found a large effect size and the model fits well, external factors not included in the model may have affected wellbeing. For example, Palmer et al., (2021) suggested treatment effects may have impacted QOL, but the current study did not collect treatment information and therefore is missing a potentially significant influencing variable.

Clinical implications

The correlations alone provide insights to clinicians supporting this population as the constructs correlated with wellbeing are connected with tangible, evidence-based interventions, including Compassion-Focussed Therapy, ACT and MAST. Thus, applying these in PMBT could improve wellbeing, a less tangible construct with multiple associated interventions but one which brings improved oncology outcomes (Gibson & Graber, 2020; Lamba et al., 2018; Noll, Sullaway & Wefel, 2019). It may also be useful for clinicians to understand that someone

low on self-compassion and spirituality might be high in PI; and younger people and non-males may have lower self-compassion, spirituality, and PF. Although an empirical question for future research, these profiles and processes might influence how an intervention is received and practiced.

The regression findings of PF, but not PI, as a significant predictor indicate increasing PF (rather than decreasing PI) would be beneficial for wellbeing in PMBT. This is typically achieved through ACT which has been shown to be successful in a small sample of primary BT (Kangas, 2015), other neurodegenerative conditions (Gould et al., 2024), and cancer (Fang et al., 2022).

The present study confirms the merit of implementing interventions to support the spiritual needs of people with PMBT. For example, dignity therapy aimed to improve meaning and purpose in palliative care patients and was found to improve depression and anxiety in a cancer sample with 4 GBM participants (Julião et al., 2014). Group reminiscence therapy had positive results in a malignant and non-malignant glioma sample (Zhao, 2021). Interventions incorporating both psychological and spiritual elements, including those supporting people to make meaning of their experiences (MAST and CALM) have produced positive results on psychological, QOL, and existential measures in samples including participants with PMBT (Jones, Ownsworth & Shum, 2015; Ownsworth et al., 2022; Ownsworth et al., 2023; Loughan et al., 2022).

These suggestions align with UK NICE guidelines recommending CBT, which includes ACT, for depression and anxiety (NICE 2022; NICE, 2011), and spiritual support for cancer patients (NICE, 2004; NICE, 2019).

Findings related to uncontrollable variables of gender, age, and time-since diagnosis hold interesting implications for interventions. Previous research indicates tumour detection is the most distressing part for patients (Goebel, von Harscher & Mehdorn, 2010) potentially due to fear of short prognoses, treatments, and impairments (Acquaye et al., 2019; Chieffo et al., 2023; Weller, 2020; Wen et al., 2020). The current study found a longer time-since diagnosis significantly predicted wellbeing. Whilst the causes of this improvement remain unclear and wellbeing might improve naturally with time, these findings and previous research imply offering psychological support closer to diagnosis for PMBT is important.

The regression results hold regardless of age. Thus, the suggested interventions could be applied across the adult lifespan. However, the correlations showed these constructs shifted with age. ACT and spirituality interventions have been adapted for older and younger adults (e.g. Yee Wong's 2019 spirituality and aging support groups; Scarlora et al.'s 2022 adolescent spiritualty intervention; Gould et al.'s 2022 ACT for older adults; and Airdrie's 2022 ACT for younger adults with PMBT). As such, accommodations for different ages should be made. It is important to consider the cognitive and physical impact of PMBT and its treatments when adapting interventions. However, ACT and spiritual interventions have been useful in populations with these considerations (e.g. Ambridge, Fleming & Henshall 2020; Craig et al., 2018; Gould et al., 2024; Hall & Beatty, 2014). Interventions might need to account for potential gender differences in emotional expression, reporting, and coping due to the differences found in this population. However, more research is needed to fully understand this connection.

The insignificant results of the SCS-SF mean score imply increasing self-compassion in PMBT may not be as useful as focusing on timely provision of PF and spirituality interventions. However, the second regression (Appendix 11) implies increasing self-compassion, rather than decreasing self-criticism, might be beneficial for this group. This could be implemented through interventions including Compassion-Focussed Therapy (Gilbert, 2009) and Mindful Self-Compassion (Germer & Neff, 2019) which have been successful in cancer studies but remain unexplored in PMBT.

The results not only provide insights for psychological intervention but other clinical contacts. They show wellbeing is influenced by many factors that could be considered when = professionals are interacting with, assessing, or formulating the experiences of people with PMBT, including their time of diagnosis, gender, sense of meaning and purpose, ability to adapt to challenges, and kindness towards themselves. This holistic approach aligns with NHS England's holistic needs assessments for personalised care and support planning (NHS England, 2021).

Future research

The findings, implications, and limitations present an interesting launchpad for future research, fitting timely with the UK's current drive for funding high-quality brain tumour research, including the National Institute for Health and Care Research recent grants for example (NIHR, 2024).

Longitudinal studies are superior to cross-sectional designs to explore the causative relationship between variables. Experimental studies, including RCTs or repeated measures

designs, evaluating the impact of proposed interventions over time would be novel for self-compassion interventions and extend existing findings on ACT (Kangas, 2015) and existential wellbeing interventions (e.g. MAST, CALM) in BT populations for PMBT specifically.

To address the limitations of the current study, future research could separate and explore sex and gender differences. Qualitative research would contribute to understanding the processes of the investigated constructs among individuals. Other confounding and mediator variables not included in this study, such as treatment, cognitive decline, race, ethnicity, social support, socio-economic status (Evans et al., 2021), and other psychological constructs including resilience and hope (Solano et al., 2016) could shed further light on wellbeing in PMBT. It also remains unclear why a longer time-since diagnosis predicts better wellbeing; whether this is due to treatment effects, adjustment, outliving prognoses, cognitive impairment, or other mechanisms, should be explored. Finally, future studies could be administered by researchers or healthcare professionals to ensure eligibility and clear understanding of questions; however, this is less realistic for quantitative research. Caregivers' views on the aspects of interest in the person they care for could also be captured.

Conclusion

The current study provides an understanding of wellbeing in an under-researched cancer population who face devastating physical, emotional, functional, and cognitive impacts, and poor prognoses. It provided evidence to show high levels of PF, spirituality, and self-compassion, and being male, predict better wellbeing. The role of self-compassion, gender, and other potentially related variables would be fruitful to explore further. Results imply it may be

important to bolster PF, spirituality, and self-kindness when navigating the distress, uncertainty, and existential impact of PMBT. The impact of interventions supporting this should be researched in this specific population.

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Appendix 1

Ethics approval

School of Health, Science and Wellbeing

ETHICAL APPROVAL FEEDBACK

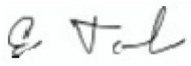
Researcher name:	Katie Peters
Title of Study:	SU_23_033: *Does time since diagnosis, self-compassion, psychological flexibility and spirituality predict mental wellbeing in people with a primary malignant brain tumour?*
Status of approval:	Approved

Thank you for addressing the committee's comments. Your research proposal has now been approved by the Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal. This approval is only valid for as long as you are registered as a student at the University.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

Signed: **Date: 01.12.2023**



Dr Edward Tolhurst; Ethics Co-ordinator for Health

Appendix 2: Study adverts

Social Media

Video

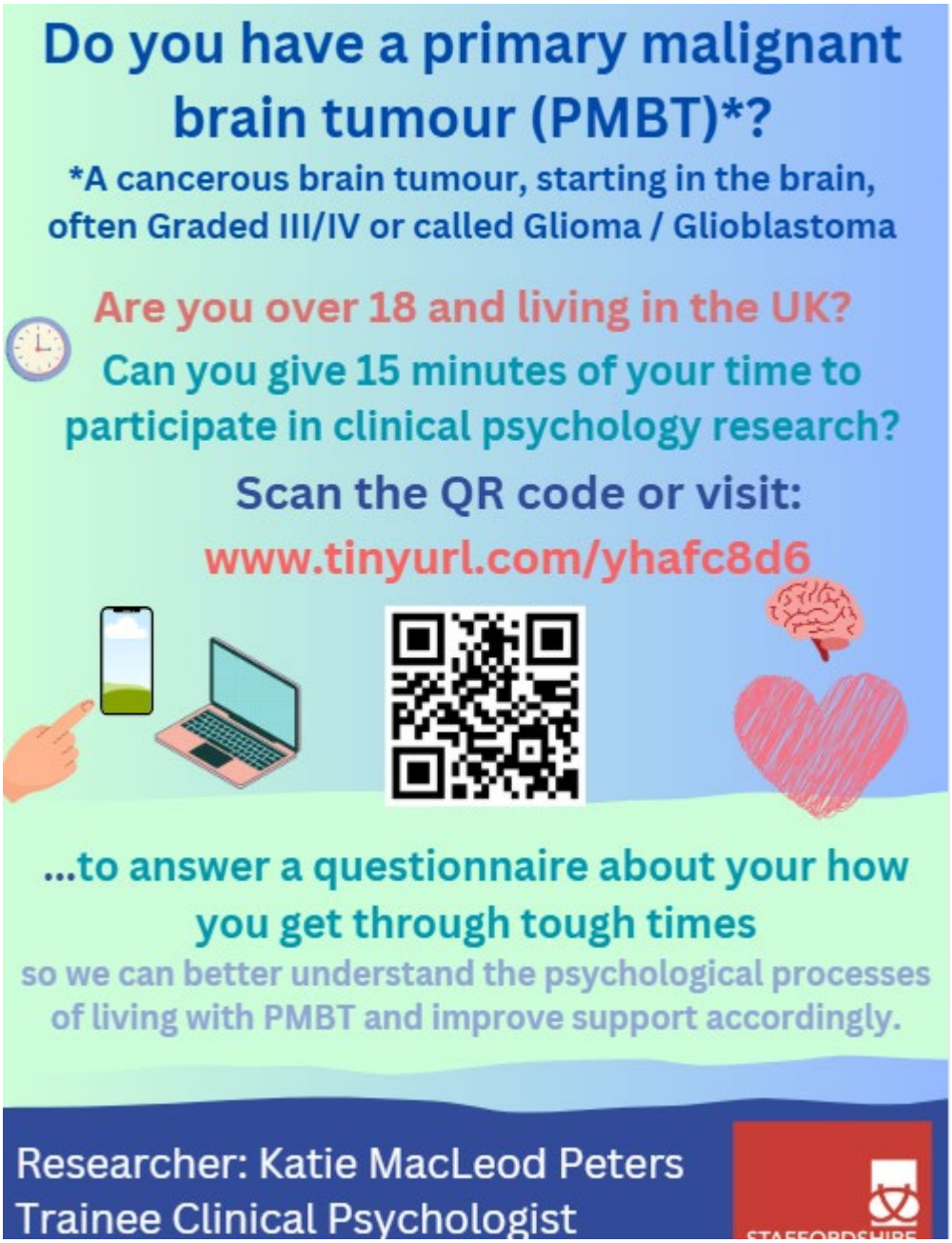
https://www.facebook.com/katie.macleod.peters/videos/436532828730657

Text

This 15 min survey is for adults, living in the UK, with a primary malignant brain tumour to contribute to my latest research on what supports people to live well with this diagnosis:

http://tinyurl.com/yhafc8d6 DM me if you have any questions or issues with the link! Thanks so much

Appendix 3: Study poster



Appendix D

INFORMATION SHEET FOR PARTICIPANTS

27.9.23 Version 2

Project Reference Number: SU_23_033

Title of study

Does the length of time since diagnosis, self-compassion, psychological flexibility and spirituality predict mental wellbeing in people with a primary malignant brain tumour (PMBT)?

Invitation Paragraph

I'm Katie, a trainee clinical psychologist. I would like to invite people with a primary malignant brain tumour to take part in this research which is part of my professional doctorate in clinical psychology. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. My contact details are at the

end of this information sheet. Please only participate if you have a diagnosis of a primary malignant brain tumour.

What is the purpose of the study?

This study will investigate whether the length of time since the diagnosis of PMBT and self-reported levels of spirituality (finding purpose and meaning in life), self-compassion (being kind to yourself) and psychological flexibility (continuing to do things that are important to you despite distress and challenges) are important in predicting mental wellbeing in people with a primary malignant brain tumour (PMBT). The length of time since diagnosis will also be considered in relation to what impacts wellbeing.

The psychological toll of living with a primary malignant brain tumour (PMBT) is well-documented, such as anxiety, low mood and lower levels of quality of life. Understanding, though, what might lessen this remains unexplored as participants with PMBT as they are underrepresented in wider cancer studies. Psychological flexibility and self-compassion have been shown in other cancer populations to improve psychological outcomes, and improving psychological outcomes has been found to positively influence physical outcomes. The results can hopefully inform the nature of psychological support for those with this diagnosis.

Why have I been invited to take part?

You have been invited if you are an adult (over the age of 18), living in the UK with a primary malignant brain tumour (PMBT, a tumour that originated in the brain that is cancerous). You are welcome to ask a family member, carer or friend to read the questions to you and input your answers on your behalf if you require this help. If you do this, please make sure the answers are still your own opinion and not that of anyone else. The questionnaire is only available in English so you or they need to be able to read and respond in English. As UK services and treatment pathways differ across countries, only participants in the UK are invited to take part in this current study.

What will happen if I take part?

If you choose to take part, you will be asked to complete a consent form after which you will be asked to complete four questionnaires that take around 15 minutes to complete in total, not including the time spent

reading this sheet and the debrief page at the end. The questionnaires ask you about who you are (age, gender, tumour diagnosis), spirituality (how you interpret life's events), self-

compassion (how you speak to yourself in hard times) and psychological flexibility (how you approach life according to your values). It may take longer depending on your circumstances and symptoms.

The questionnaire is available online or you can email me to request a paper copy that I will send to you with a stamped addressed envelope: p028856l@student.staffs.ac.uk.

Your answers to the questionnaire will be anonymised using a unique participant code you will choose consisting of 2 random letters and 4 random numbers. Please write this down so you can reference it if you want to your withdraw consent. Anonymised questionnaires will be combined. Your answers will not be personally identifiable or traceable to you. All participant responses will be inputted into a computer programme that enables analysis of numerical data. The consent form and questionnaire ask for your email address only if you want to contribute to how the study results are communicated and shared. This will not be connected to your questionnaire answers and will only be used to contact you when the results are ready.

Do I have to take part?

No. Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about

taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep. If you are answering the questionnaire online, a consent page is presented at the start of the survey for you to write your initials. By submitting the online questionnaire this assumes you have consented to take part; however, you can contact the researcher if you wish to withdraw your consent up until up until two weeks after completing the questionnaire.

What are the possible risks of taking part?

Answering the questions may cause you some distress as you are invited to reflect on how you are feeling emotionally, as well as how you deal with difficult times. Please remember you can stop the questionnaire and withdraw your consent to participate if you are experiencing a level of distress that means you are unable to continue.

If answering this questionnaire has highlighted any emotional challenges you would like support with, you can:

- Talk to your GP about accessing psychological support.
- Call Samaritans 116 123 (open all day, everyday).
- Access support and information from charities, including the following who all provide support to people living with a brain tumour, their families, friends and carers

- https://www.thebraintumourcharity.org/ Email: support@thebraintumourcharity.org or call: 0808 800 0004. They also have a free counselling service: https://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/free-counselling-service/
- https://brainstrust.org.uk/ 24/7 Helpline: 01983 292 405 Email: hello@brainstrust.org.uk
- https://www.headway.org.uk/ Call 0808 800 2244. Open 9am - 5pm, Monday to Friday, but you can leave an answerphone message at any time.
- https://www.braintumoursupport.co.uk/ Support enquiries: 01454 422701, Email: support@braintumoursupport.co.uk

What are the possible benefits of taking part?

There are no direct benefits to participating in this study but it is hoped that by obtaining the views of people living with a primary malignant brain tumour that the results will contribute to the knowledge base about what whether spirituality, self-compassion and psychological flexibility impact the wellbeing of those living with PMBT.

Data handling and confidentiality

Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2016 (GDPR).

As your answers will be anonymised and combined with the other responses, they cannot be traced to you personally. The researcher and their two supervisors will have access to this anonymous and encrypted data for data analysis purposes.

Your consent form will be kept separate to any of your questionnaire responses and will be stored securely in a locked cabinet on university premises by the research supervisor. Your questionnaire responses will be stored securely on an encrypted online database, on a password protected laptop and memory stick. The consent forms will be destroyed three months after study completion. Anonymised data in the questionnaires will be stored for 10 years, aligning with university policy and GDPR. At that point, any files will be deleted, and the hard copies and memory stick will be destroyed.

Data Protection Statement

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a 'task in

the public interest.' You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided.

What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason, until up until two weeks after completing the questionnaire. After this, the data will have been combined and analysed. Withdrawing from the study will not affect you in any way. To withdraw please contact the researcher by email: p028856l@student.staffs.ac.uk

If you choose to withdraw from the study, we will not retain any information that you have provided us as a part of this study.

What will happen to the results of the study?

The results of the study will be presented in a final research portfolio in order to obtain the doctorate in clinical psychology. This will be held at the university and can be accessed by interested parties. It will also be available on the British Library online thesis repository, EthOS, accessible by UK students holding an EthOS account. The findings may be published in articles written by myself and/or my supervisors. Results may be presented at conferences, workshops or in education settings.

If you would like to contribute to making the executive summary of this study's findings, or would like a to receive a copy of it, please email the researcher, p028856l@student.staffs.ac.uk

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Katie MacLeod Peters (trainee clinical psychologist) Email: p028856l@student.staffs.ac.uk

You can also contact Academic Supervisor: Dr Helen Scott, Research Director in Clinical Psychology, Registered Clinical Psychologist, h.scott@staffs.ac.uk

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Chair of the Staffordshire University Ethics Committee: Professor Nachiappan Chockalingam

Email: N.Chockalingam@staffs.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 5: Consent form

Consent Form

<table>
<tr><td colspan="2"><u>Title of research study</u>

Does the length of time since diagnosis, self-compassion, psychological flexibility and spirituality predict mental wellbeing in people with a primary malignant brain tumour?

Project Reference: SU_23_033</td></tr>
<tr><td><u>Researcher:</u>

Katie MacLeod Peters, Trainee clinical psychologist</td><td rowspan="2"><u>Participant Identification Number:</u>

Please create this using 2 random letters and 4 random numbers.

Write it down so you can reference it if you want to withdraw your consent and participation at any time.</td></tr>
<tr><td>Email: p028856l@student.staffs.ac.uk</td></tr>
</table>

Please read the following statements and put your initials in the box next to it if you consent to it.	Initial

I confirm that I have read the information sheet dated 27.9.23 Version 2 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation is voluntary and that I am free to withdraw at any up until two weeks after completing the questionnaire, without giving any reason, and without my medical care or legal rights being affected.	
I consent for the information collected to be used anonymously in research articles, workshops, presentations and to support other research in the future. I understand it may be shared anonymously with other researchers or for auditing purposes.	
I understand that the personal information on this sheet will be stored securely in a password protected laptop or locked cabinet, separately to my questionnaire responses, for three months after study completion before being destroyed according to NHS policy.	
I understand that the data in the questionnaire will be anonymised and stored safely before it is destroyed after 10 years according to university and GDPR regulations	
I agree to take part in the above study.	

	Researcher	**Participant**
Name	Katie MacLeod Peters	**Participant Identification Number**:
Title	Trainee clinical psychologist	

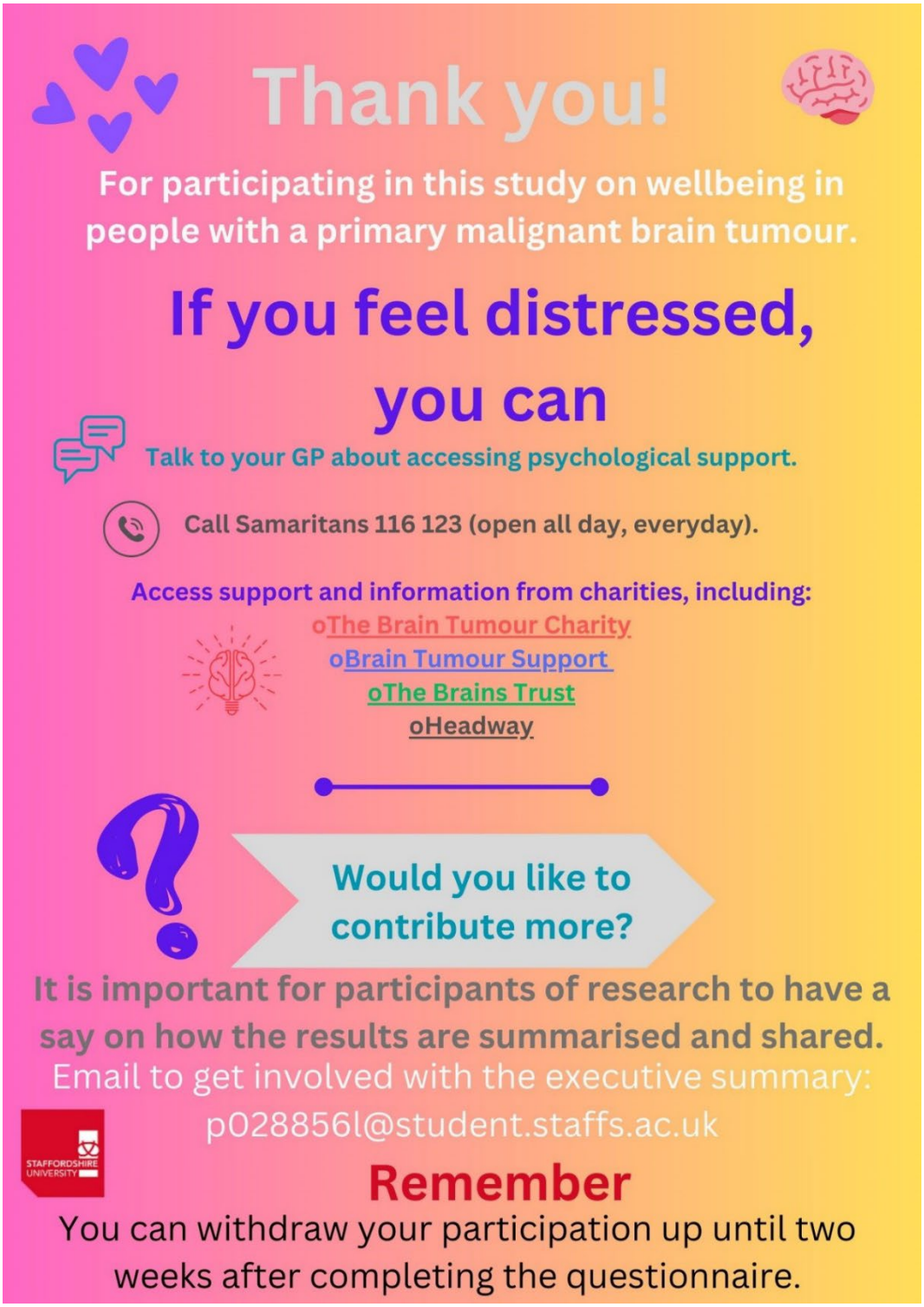
		(Pick 2 letters and 4 numbers – keep a copy of these)
Signature		
Date	30th November 2023	
Contact details	p028856l@student.staffs.ac.uk	Only provide your email address if you want to contribute to how the study results are shared and communicated

Appendix 6: Demographic questions

1. **How old are you? (In years)**
2. **How do you describe your gender? (Male/ Female/ Non-binary / Trans / prefer not to say / other)**
3. **What type of brain tumour do you have? Astrocytoma/ Anaplastic astrocytoma / Glioblastoma / Oligodendroglioma / Anaplastic oligodendroglioma / Diffuse midline glioma (or diffuse intrinsic pontine glioma – DIPG) / Optic nerve glioma / Ependymoma / Anaplastic ependymoma / Medulloblastoma / Meningioma / Atypical meningioma / Anaplastic meningioma / Brain metastases / Other (please describe) [Free text box] / I don't know what type of brain tumour I have**
4. **How long ago were you diagnosed with PMBT? Please answer in months and / or years, e.g. "4 months" or "2 years and 3 months" or "1 year". (in months and**

years) [time since diagnosis]

Appendix 7: Debrief sheet



Appendix 8: Full scores and data for all variables

Descriptive statistics

Descriptive Statistics

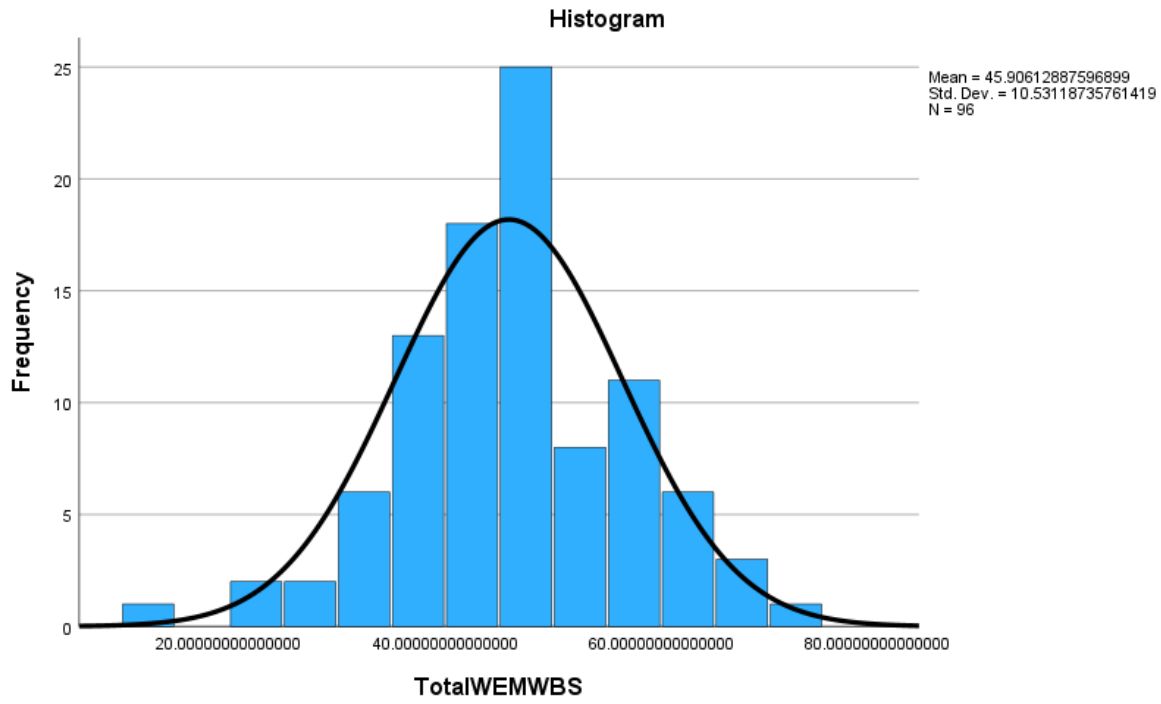
	Mean	Std. Deviation	N
TotalWEMWBS	45.863157894736840	10.578591916833217	95
Q6AgeInYears	49.74	11.804	95
Q9TimeSinceDianosisInMonthsIV1	42.999	51.4360	95
TotalSCSSFMean	2.974561403508771	.805480790101537	95
MPFIFlexibility	3.784210526315787	.932922808718651	95
MPFIInflexibility	3.104385964912282	.811410974209777	95
TotalFacit	25.19	11.013	95
Gender Dummy Variable	.4000	.49250	95

Wellbeing

Statistics

TotalWEMWBS

N	Valid	96
	Missing	0
Mean		45.906128875968990
Median		46.000000000000000
Mode		48.000000000000000
Std. Deviation		10.531187357614188
Skewness		-.169
Std. Error of Skewness		.246
Kurtosis		.200
Std. Error of Kurtosis		.488
Range		56.000000000000000



Age

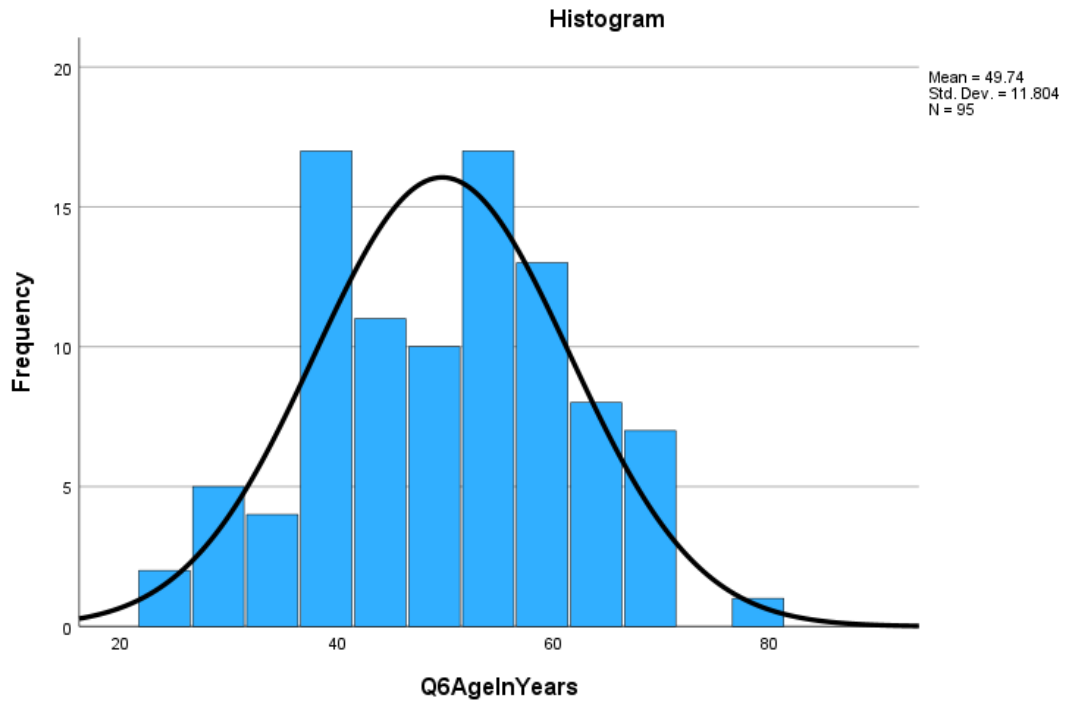
Statistics

Q6AgeInYears

N	Valid	95
	Missing	0
Mean		49.74
Median		50.00

Mode	37[a]
Std. Deviation	11.804
Variance	139.345
Skewness	-.084
Std. Error of Skewness	.247
Kurtosis	-.623
Std. Error of Kurtosis	.490
Range	54

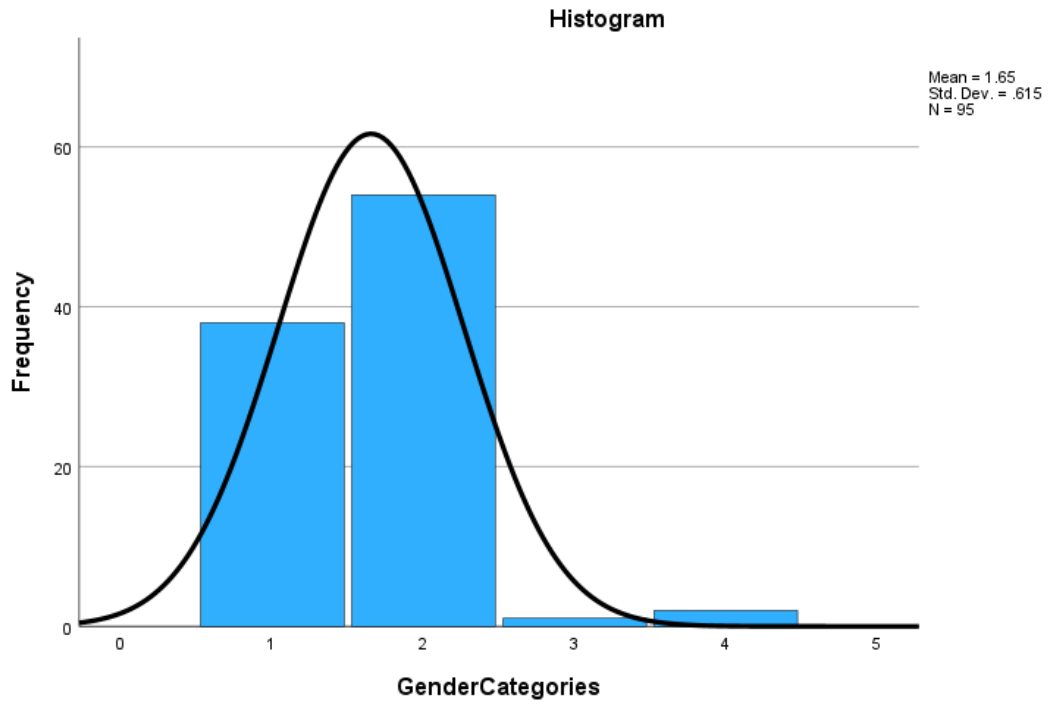
a. Multiple modes exist. The smallest value is shown



Gender

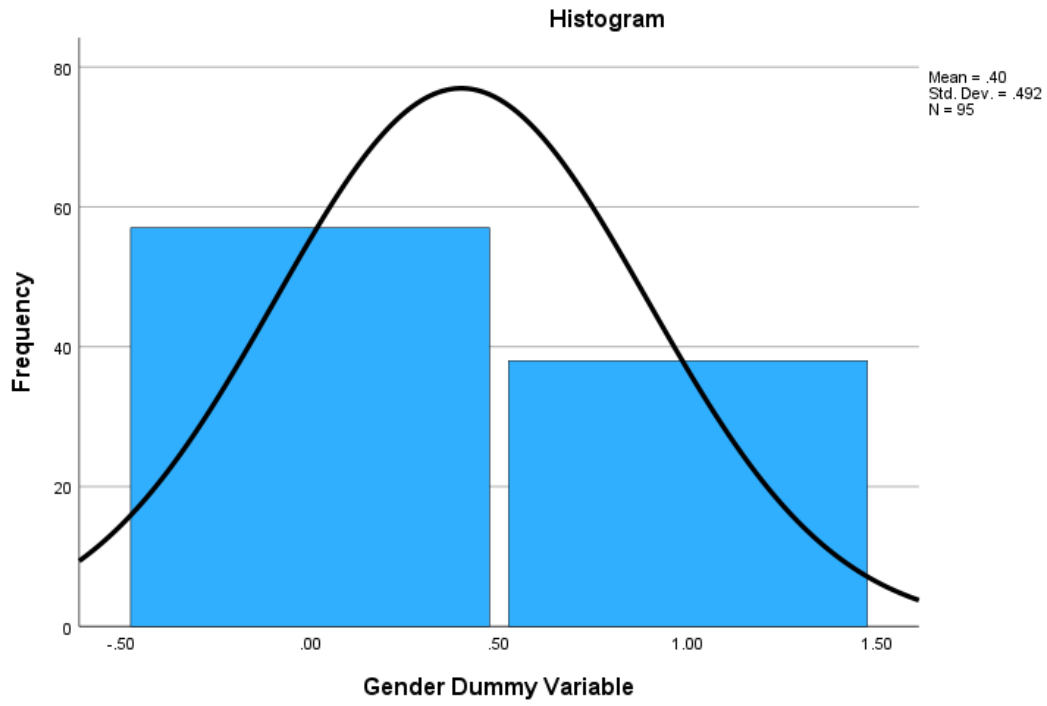
GenderCategories

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	38	39.6	40.0	40.0
	Female	54	56.3	56.8	96.8
	NonBinary	1	1.0	1.1	97.9
	NotDisclosed	2	2.1	2.1	100.0
	Total	95	99.0	100.0	
Missing	System	1	1.0		
Total		96	100.0		



Gender Dummy Variable

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	.00	57	60.0	60.0	60.0
	1.00	38	40.0	40.0	100.0
	Total	95	100.0	100.0	



Tumour type

Statistics

		Q8BTType	Q8BTOther	Malignant
N	Valid	95	95	95
	Missing	0	0	0
Mean				.96
Std. Deviation				.202
Range				1

Q8BTType

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Anaplastic astrocytoma	16	16.8	16.8	16.8
	Anaplastic oligodendroglioma	7	7.4	7.4	24.2
	Astrocytoma	18	18.9	18.9	43.2
	Don't Know	3	3.2	3.2	46.3
	Glioblastoma	40	42.1	42.1	88.4
	Meningioma	3	3.2	3.2	91.6
	Other	8	8.4	8.4	100.0
	Total	95	100.0	100.0	

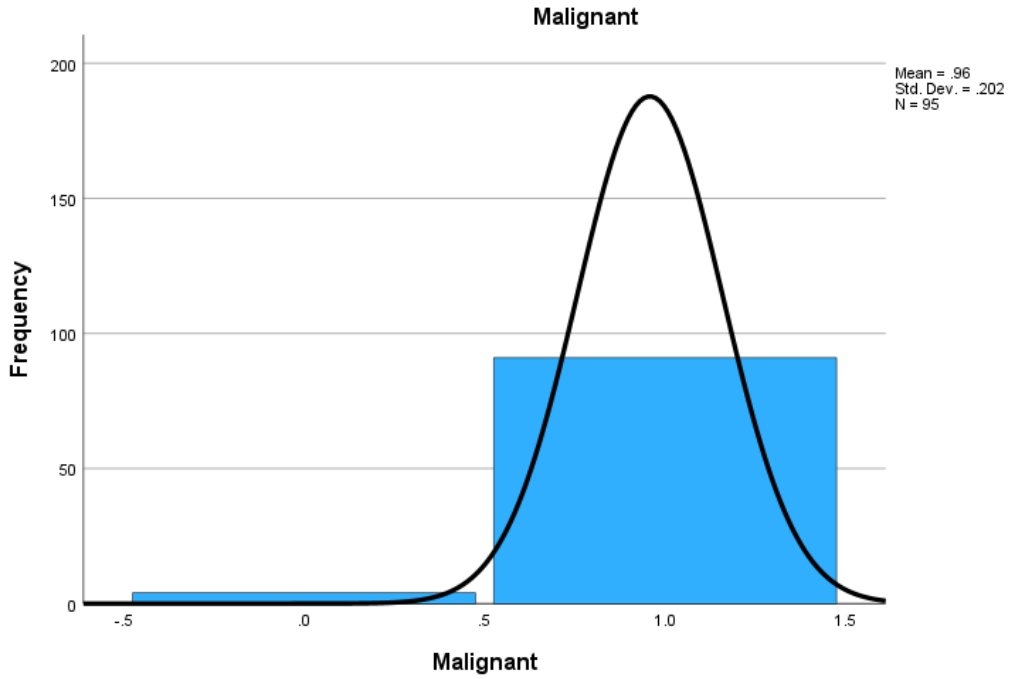
Q8BTOther

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		88	92.6	92.6	92.6
	Acoustic neuroma	1	1.1	1.1	93.7

	Central Neurocytoma	1	1.1	1.1	94.7
	Choroid plexus	1	1.1	1.1	95.8
	Grade 2 Astrocytoma	1	1.1	1.1	96.8
	Myxoid Chondrosarcoma	1	1.1	1.1	97.9
	Oligodendroglioma	1	1.1	1.1	98.9
	Vestivular schwanoma	1	1.1	1.1	100.0
	Total	95	100.0	100.0	

Malignant

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	4	4.2	4.2	4.2
	Yes	91	95.8	95.8	100.0
	Total	95	100.0	100.0	



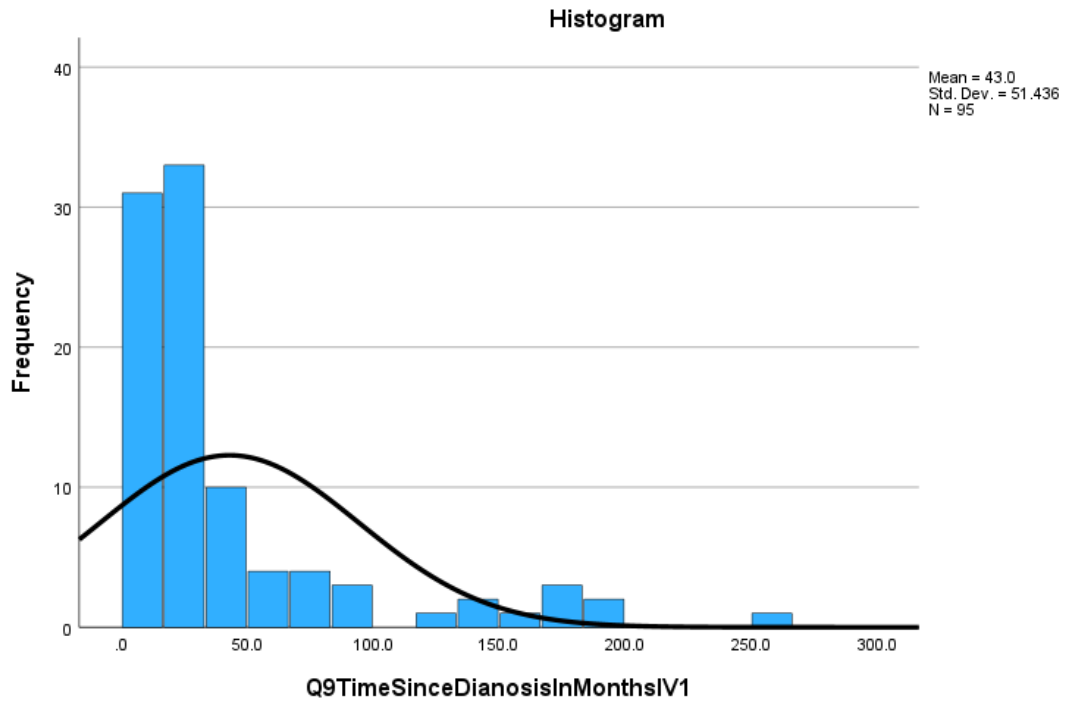
Time since diagnosis

Statistics

Q9TimeSinceDianosisInMonthsIV1

N	Valid	95
	Missing	0
Mean		42.999
Median		25.000
Mode		30.0
Std. Deviation		51.4360
Variance		2645.664

Skewness	2.221
Std. Error of Skewness	.247
Kurtosis	4.721
Std. Error of Kurtosis	.490
Range	264.0



Self-compassion

Statistics

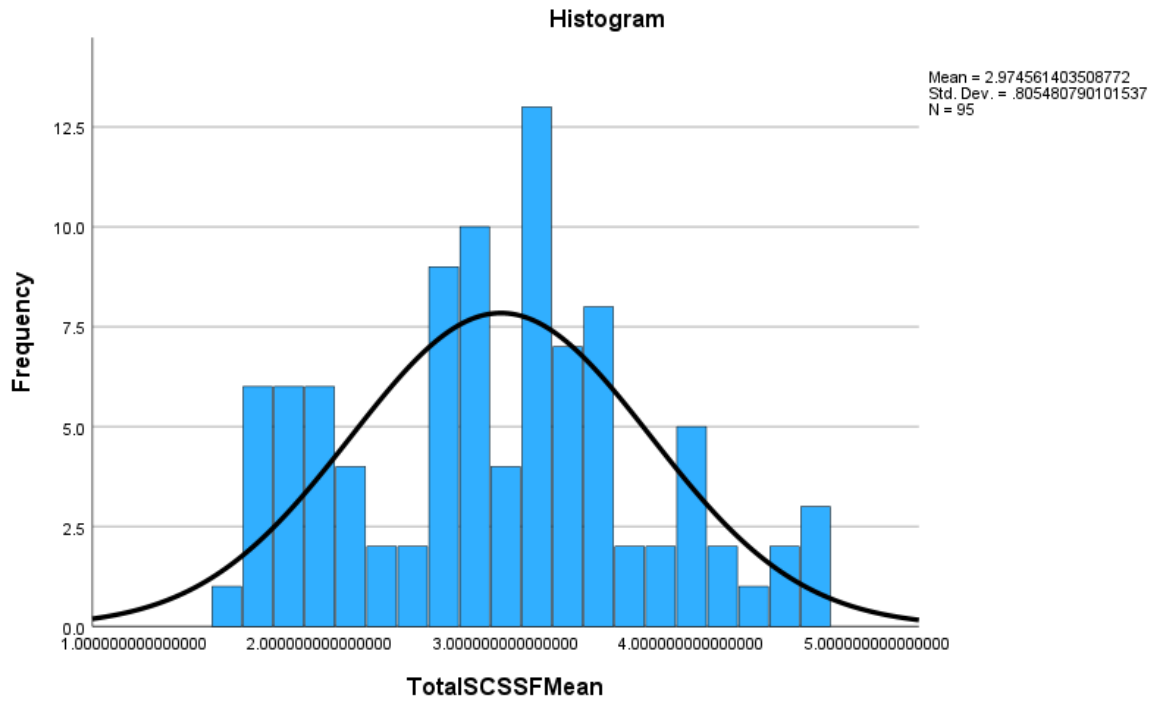
TotalSCSSFMean

N	Valid	95
	Missing	0
Mean		2.97456140350 8772
Median		3.00000000000 0000
Mode		2.91666666666 6667
Std. Deviation		.805480790101 537
Variance		.649
Skewness		.195
Std. Error of Skewness		.247
Kurtosis		-.510
Std. Error of Kurtosis		.490
Range		3.25000000000 0000

Statistics

TotalSCSSF

N	Valid	95
	Missing	0
Mean		35.6947
Std. Error of Mean		.99169
Median		36.0000
Mode		35.00
Std. Deviation		9.66577
Skewness		.195
Std. Error of Skewness		.247
Kurtosis		-.510
Std. Error of Kurtosis		.490
Range		39.00



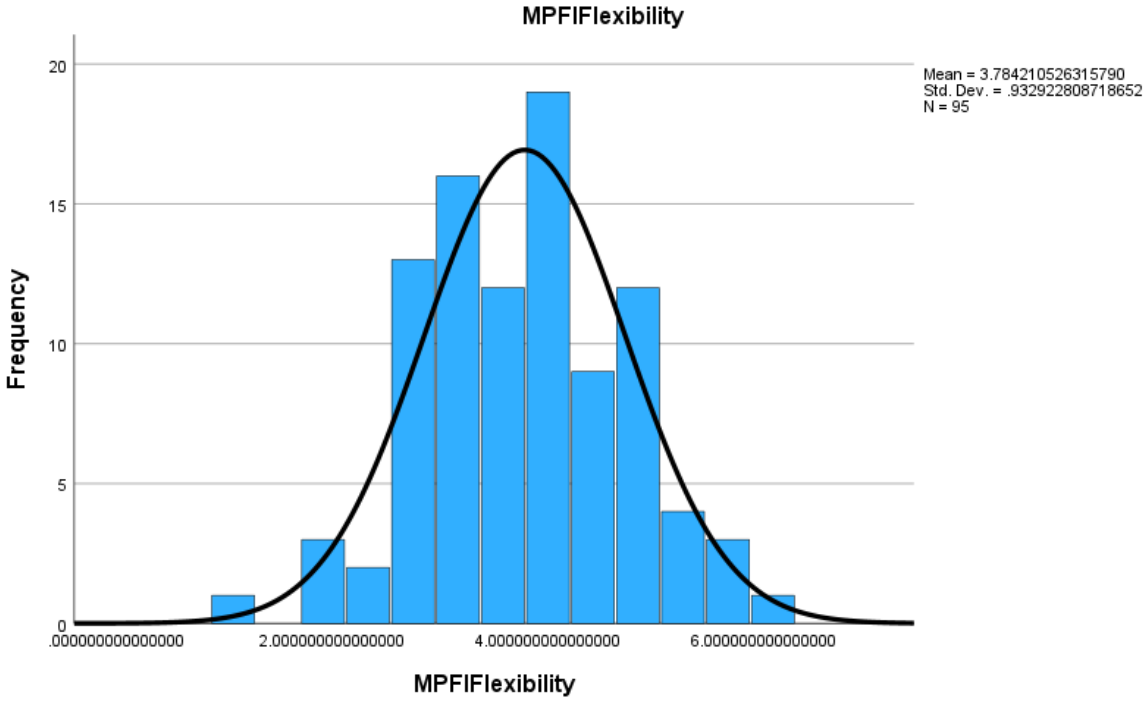
Psychological flexibility

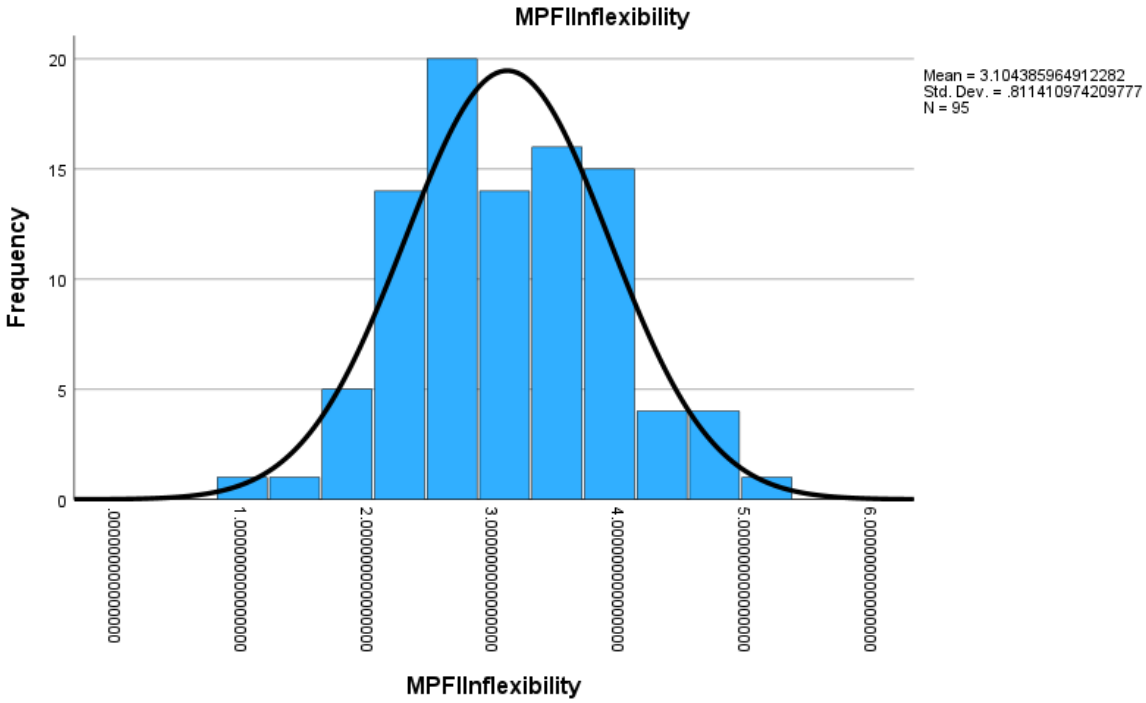
Statistics

		MPFIFlexibility	MPFIInflexibility
N	Valid	95	95
	Missing	0	0
Mean		3.78421052631 5791	3.10438596491 2282
Median		3.83333333333 3334	3.00000000000 0000

Mode	3.166666666666667[a]	3.916666666666667
Std. Deviation	.932922808718652	.811410974209778
Variance	.870	.658
Skewness	-.020	.125
Std. Error of Skewness	.247	.247
Kurtosis	-.027	-.243
Std. Error of Kurtosis	.490	.490
Range	4.916666666666667	4.250000000000000

a. Multiple modes exist. The smallest value is shown


MPFIFlexibility
Mean = 3.784210526315790
Std. Dev. = .932922808718652
N = 95
Frequency
20
15
10
5
0
.000000000000000
2.000000000000000
4.000000000000000
6.000000000000000
MPFIFlexibility

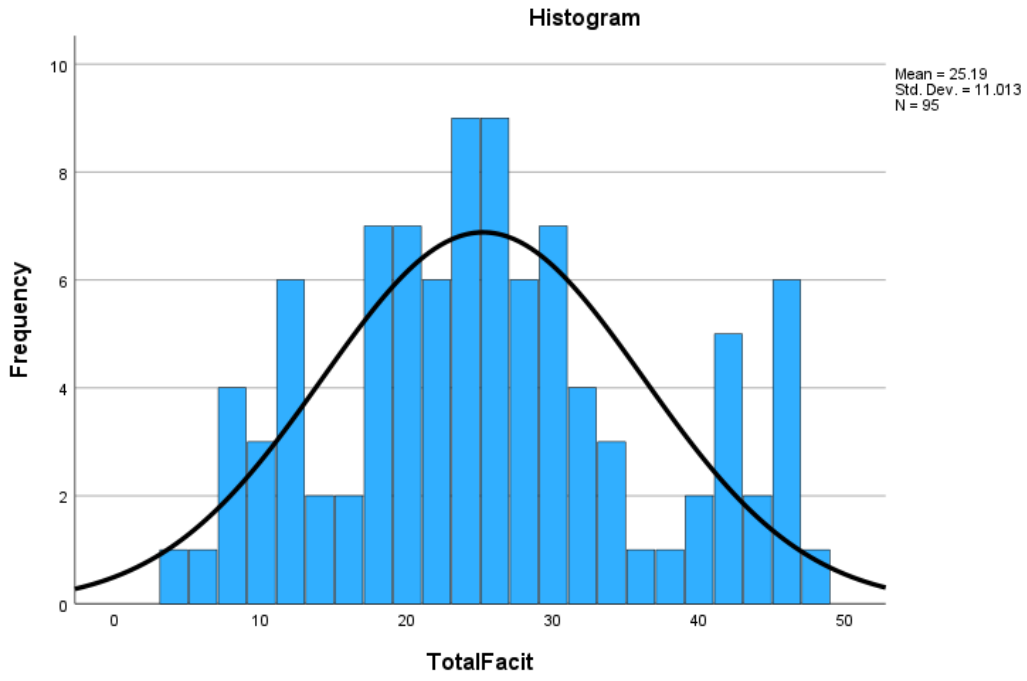

MPFIInflexibility
Mean = 3.104385964912282
Std. Dev. = .811410974209777
N = 95
Frequency
20
15
10
5
0
.000000000000000
1.000000000000000
2.000000000000000
3.000000000000000
4.000000000000000
5.000000000000000
6.000000000000000
MPFIInflexibility

Spirituality

Statistics

TotalFacit

N	Valid	95
	Missing	0
Mean		25.19
Median		24.00
Mode		23
Std. Deviation		11.013
Variance		121.283
Skewness		.300
Std. Error of Skewness		.247
Kurtosis		-.606
Std. Error of Kurtosis		.490
Range		44

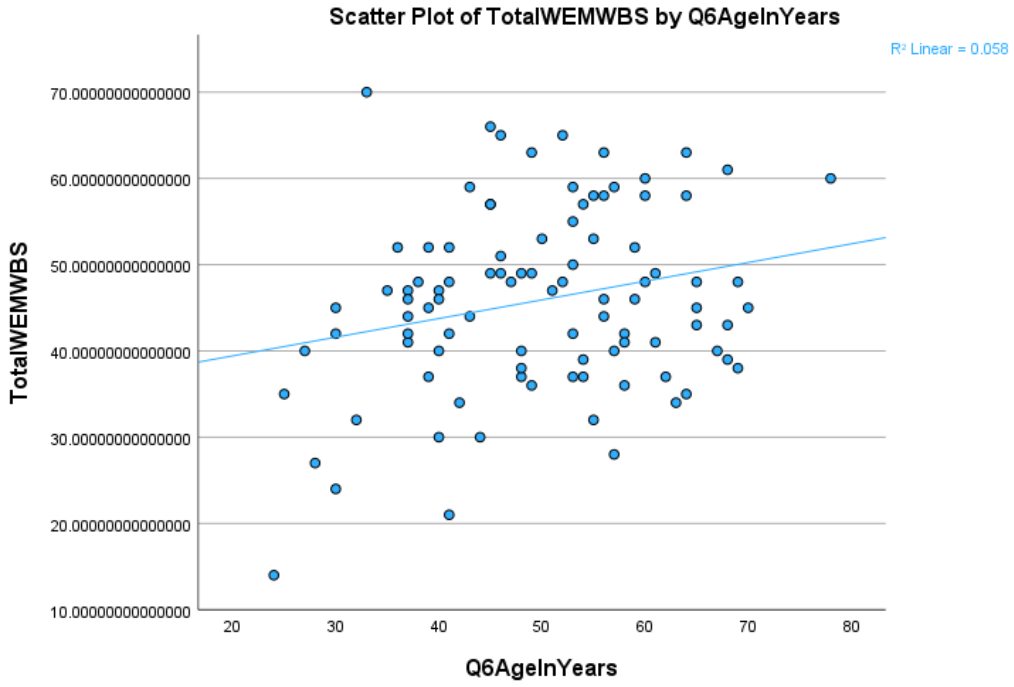


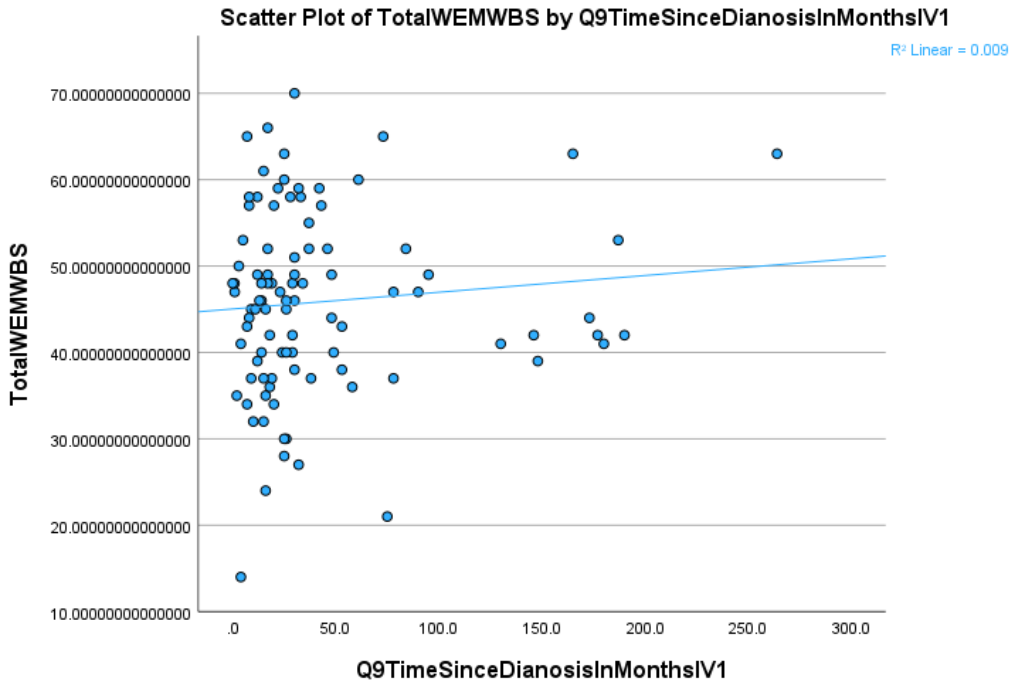
Appendix 9: Model assumptions and diagnostics tests

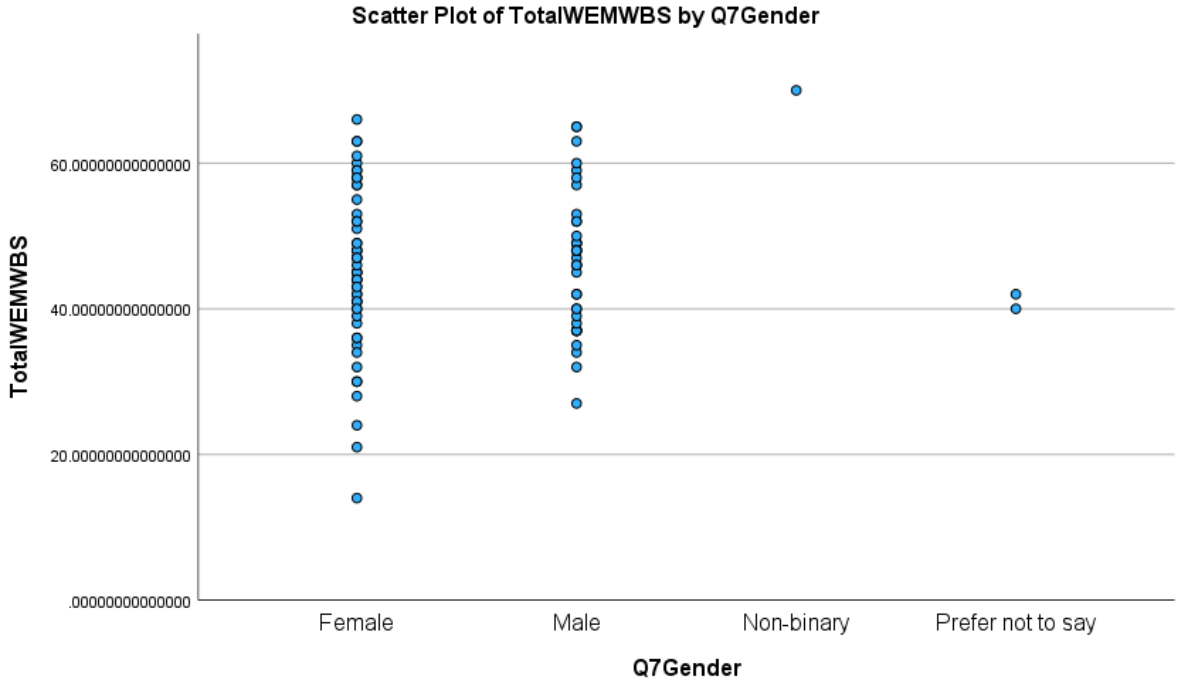
Summary of Assumptions Testing in SPSS

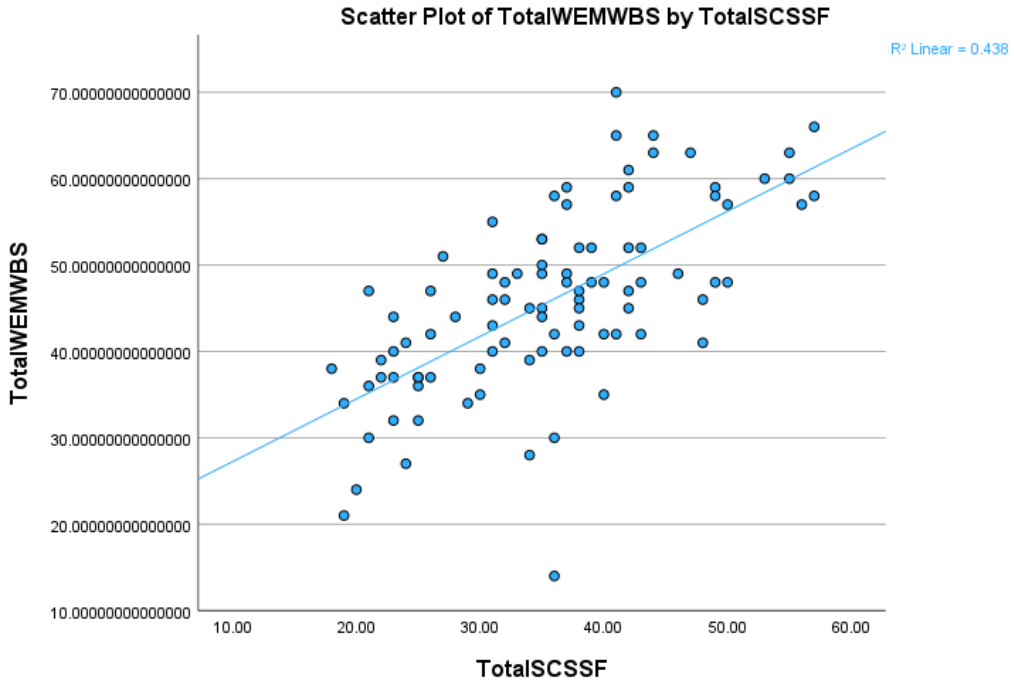
- ✓ **Linearity**: Scatterplots and partial regression plots.
- ✓ **Independence of Errors**: Durbin-Watson statistic. – in regression output
- ✓ **Homoscedasticity**: Residuals vs. predicted plot.
- ✓ **Normality of Residuals**: Histogram, Q-Q plot, Shapiro-Wilk test.
- ✓ **Multicollinearity**: VIF and Tolerance.
- ✓ **Outliers**: Cook's Distance, Standardized Residuals.

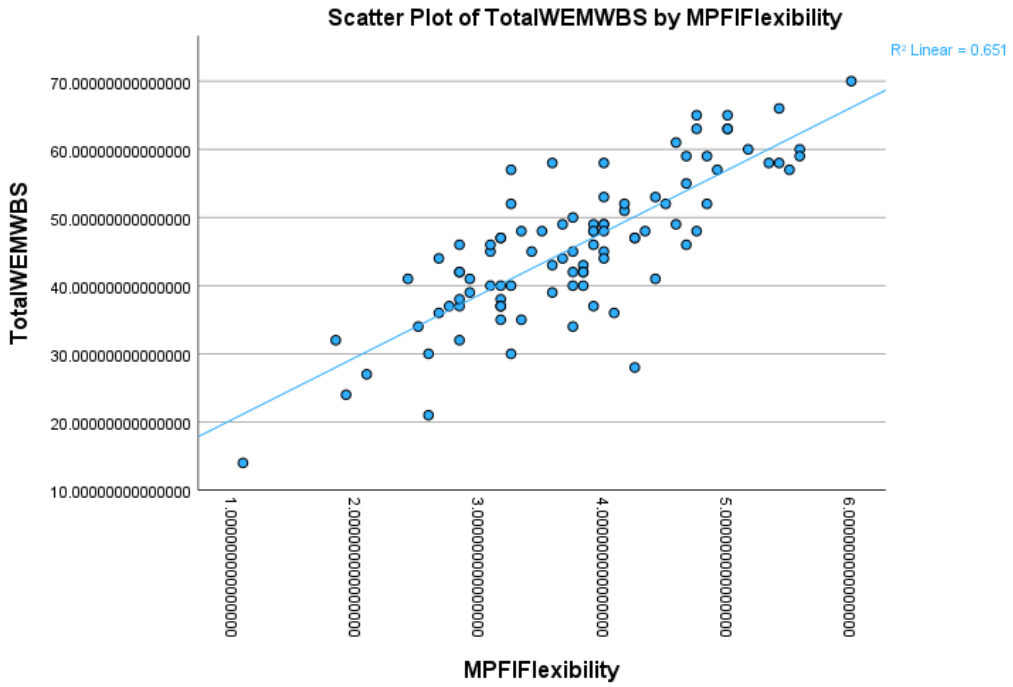
Scatterplots of predictor variables



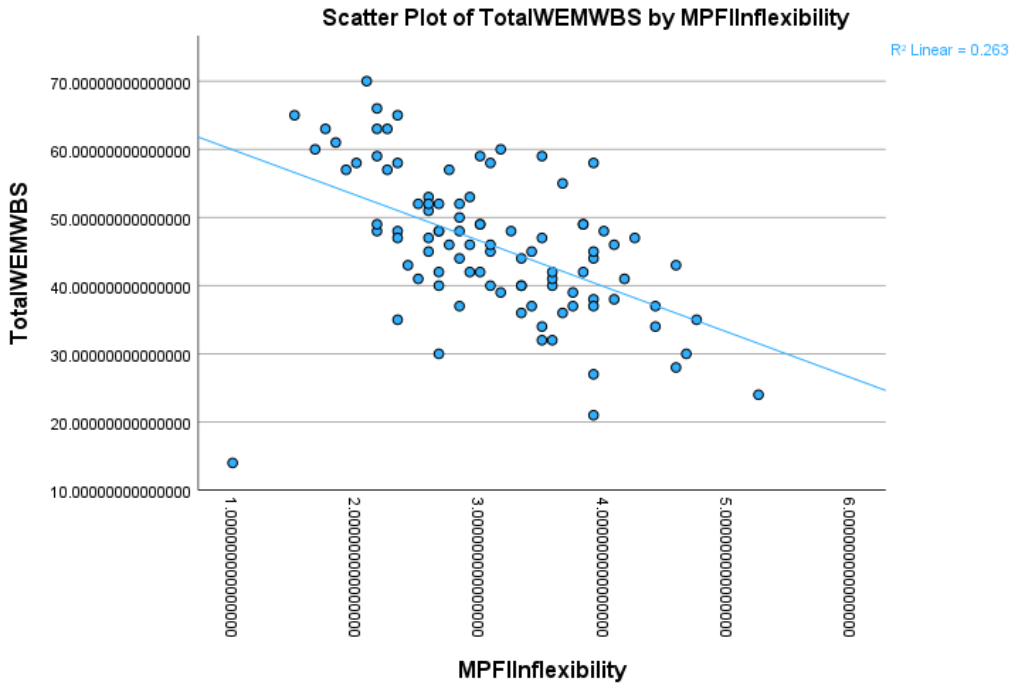

Scatter Plot of TotalWEMWBS by Q9TimeSinceDianosisInMonthsIV1
R² Linear = 0.009
70.00000000000000
60.00000000000000
50.00000000000000
40.00000000000000
30.00000000000000
20.00000000000000
10.00000000000000
TotalWEMWBS
.0
50.0
100.0
150.0
200.0
250.0
300.0
Q9TimeSinceDianosisInMonthsIV1

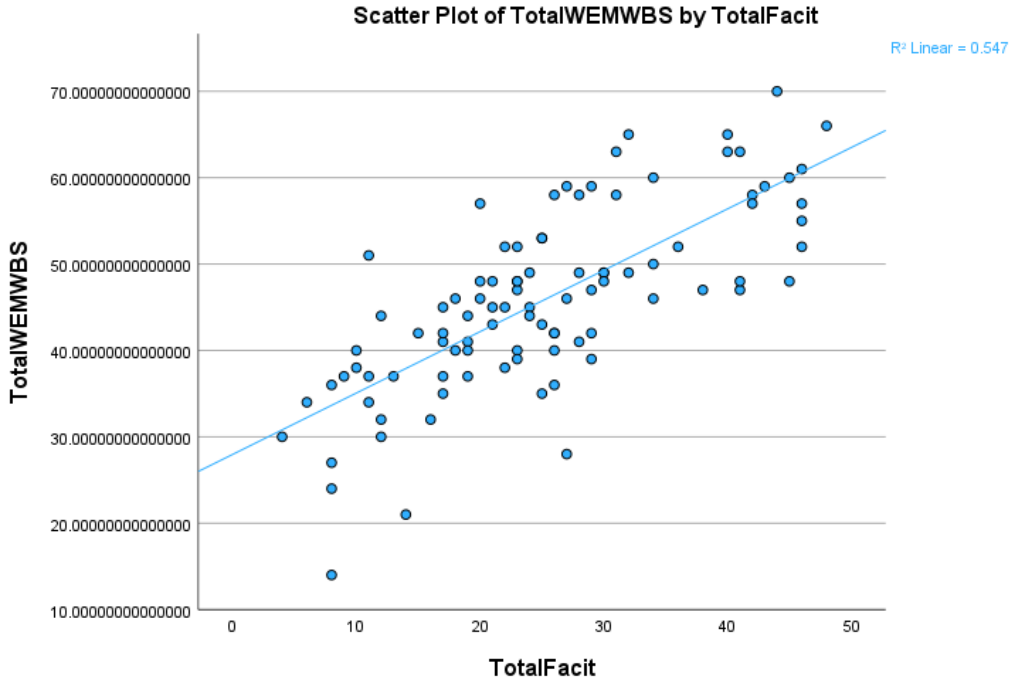

Scatter Plot of TotalWEMWBS by Q7Gender
60.00000000000000
40.00000000000000
20.00000000000000
.00000000000000
TotalWEMWBS
Female
Male
Non-binary
Prefer not to say
Q7Gender


Scatter Plot of TotalWEMWBS by TotalSCSSF
R² Linear = 0.438
TotalWEMWBS
70.00000000000000
60.00000000000000
50.00000000000000
40.00000000000000
30.00000000000000
20.00000000000000
10.00000000000000
10.00
20.00
30.00
40.00
50.00
60.00
TotalSCSSF


Scatter Plot of TotalWEMWBS by MPFIFlexibility
R² Linear = 0.651
TotalWEMWBS
70.00000000000000
60.00000000000000
50.00000000000000
40.00000000000000
30.00000000000000
20.00000000000000
10.00000000000000
1.00000000000000
2.00000000000000
3.00000000000000
4.00000000000000
5.00000000000000
6.00000000000000
MPFIFlexibility

More linear


Scatter Plot of TotalWEMWBS by MPFIInflexibility
R² Linear = 0.263
TotalWEMWBS
70.00000000000000
60.00000000000000
50.00000000000000
40.00000000000000
30.00000000000000
20.00000000000000
10.00000000000000
1.000000000000000
2.000000000000000
3.000000000000000
4.000000000000000
5.000000000000000
6.000000000000000
MPFIInflexibility


Scatter Plot of TotalWEMWBS by TotalFacit
R² Linear = 0.547
TotalWEMWBS
70.00000000000000
60.00000000000000
50.00000000000000
40.00000000000000
30.00000000000000
20.00000000000000
10.00000000000000
0
10
20
30
40
50
TotalFacit

Shapiro-Wilk test for the regression

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Standardized Residual	.066	95	.200*	.981	95	.198

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Standardized Residual Stem-and-Leaf Plot

Frequency Stem & Leaf

3.00 Extremes (=<-2.1)

4.00 -1 . 5667

5.00 -1 . 02223

11.00 -0 . 55666778999

21.00 -0 . 000011111223333444444

26.00 0 . 00000111111222222233333344

13.00 0 . 5556666778889

6.00 1 . 001233

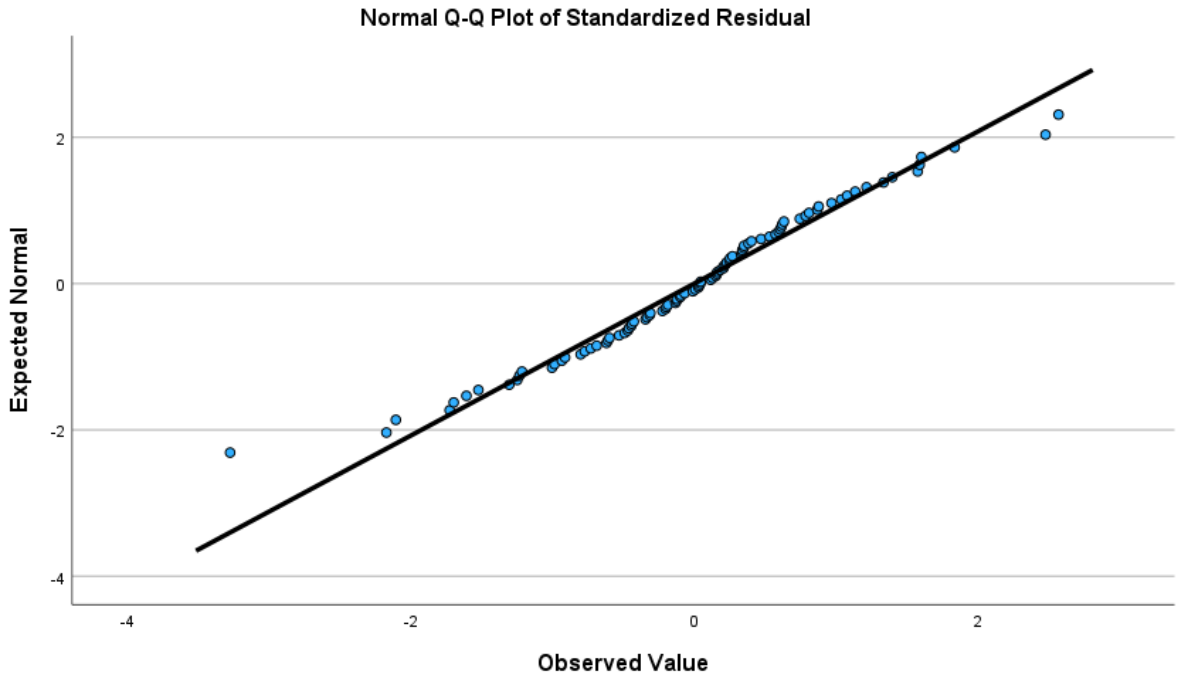
4.00 1 . 5568

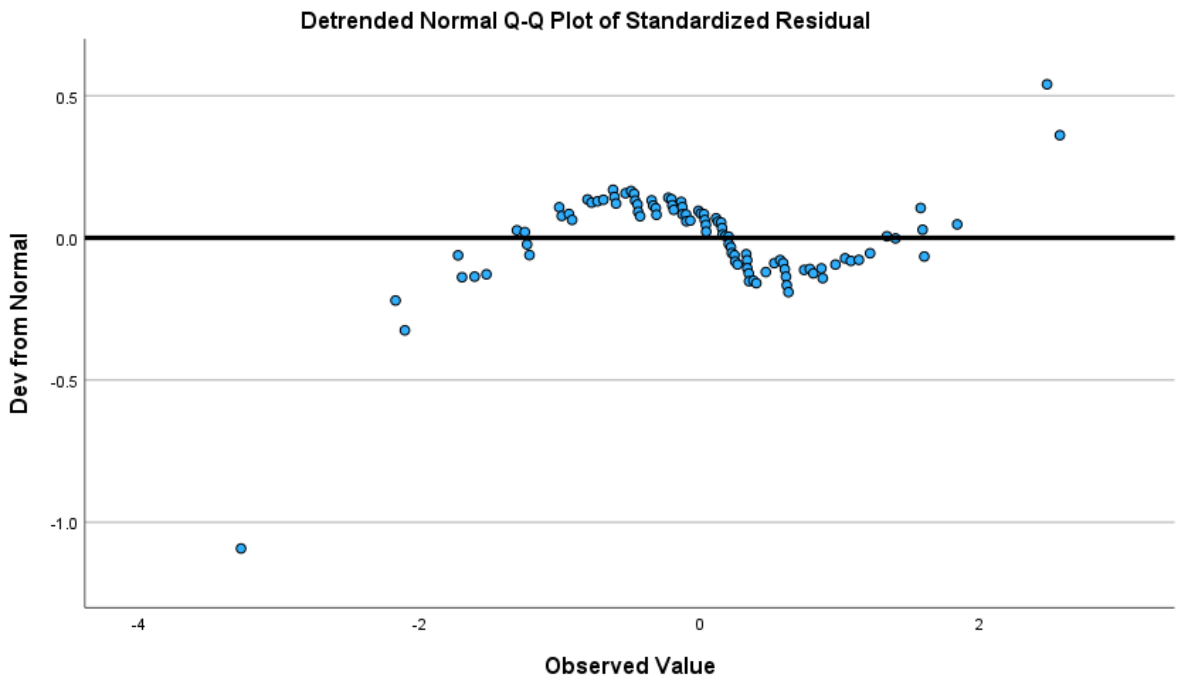
2.00 Extremes (>=2.5)

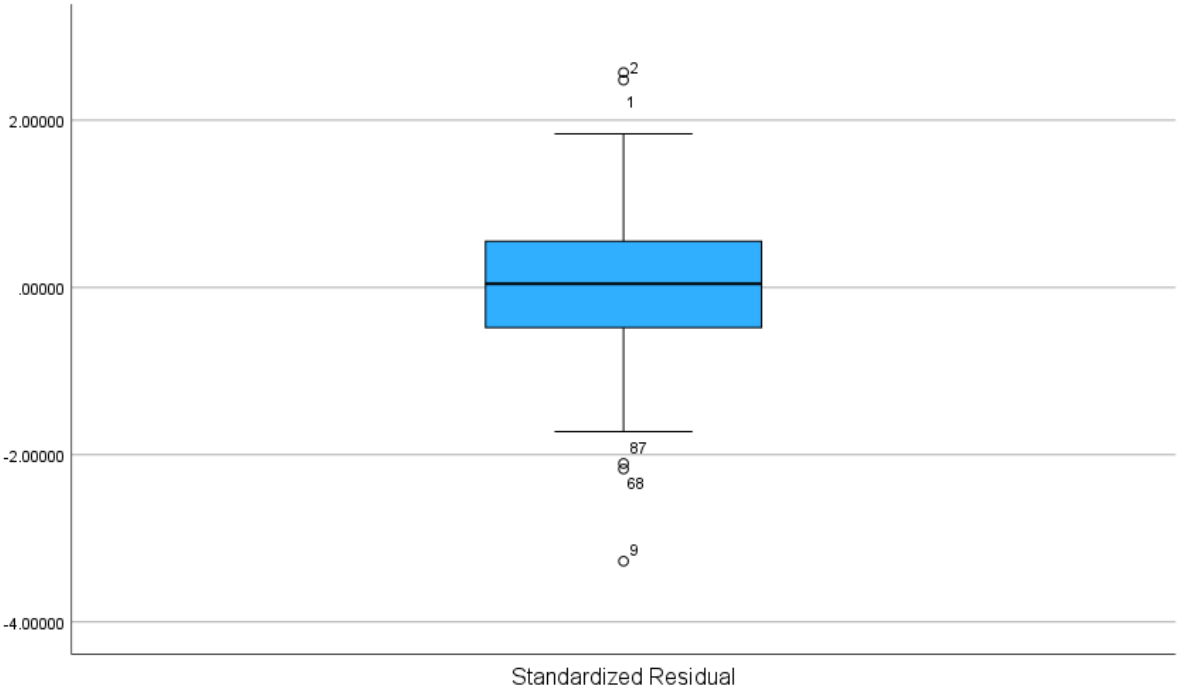
Stem width: 1.00000

Each leaf: 1 case(s)

Scatterplot of Residuals (for the regression)




Detrended Normal Q-Q Plot of Standardized Residual
Dev from Normal
0.5
0.0
-0.5
-1.0
-4
-2
0
2
Observed Value


2.00000
.00000
-2.00000
-4.00000
82
1
87
68
9
Standardized Residual

Residuals Statistics[a]

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	23.444816589355470	65.729339599609380	45.863157894736870	9.122583187759915	95
Std. Predicted Value	-2.457	2.178	.000	1.000	95
Standard Error of Predicted Value	.947	3.557	1.568	.390	95
Adjusted Predicted Value	25.256248474121094	66.235755920410160	45.948428732960290	9.021150949357127	95
Residual	-18.227163314819336	14.310361862182617	-.000000000000012	5.355845677882106	95

200

Std. Residual	-3.274	2.571	.000	.962	95
Stud. Residual	-3.435	2.642	-.007	1.012	95
Deleted Residual	-20.061510086059570	15.122238159179688	-.085270838223420	5.960158617628347	95
Stud. Deleted Residual	-3.673	2.739	-.009	1.032	95
Mahal. Distance	1.729	37.376	6.926	4.597	95
Cook's Distance	.000	.419	.015	.047	95
Centered Leverage Value	.018	.398	.074	.049	95

a. Dependent Variable: TotalWEMWBS

Appendix 10: Multiple regression analysis for seven predictors

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.862[a]	.744	.723	5.5671427234	.744	36.058	7	87	<.001	1.668

a. Predictors: (Constant), Gender Dummy Variable, TotalSCSSFMean, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, TotalFacit, MPFIInflexibility, MPFIFlexibility

b. Dependent Variable: TotalWEMWBS

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	7822.823	7	1117.546	36.058	<.001[b]
	Residual	2696.398	87	30.993		
	Total	10519.221	94			

a. Dependent Variable: TotalWEMWBS

b. Predictors: (Constant), Gender Dummy Variable, TotalSCSSFMean, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, TotalFacit, MPFIInflexibility, MPFIFlexibility

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	10.887	6.299		1.728	.087	-1.633	23.406					
	Q6AgeInYears	-.020	.052	-.022	-.386	.701	-.123	.083	.242	-.041	-.021	.878	1.139
	Q9TimeSinceDianosisInMonthsIV1	.029	.012	.143	2.543	.013	.006	.052	.094	.263	.138	.929	1.077
	TotalSCSSFMean	1.520	1.247	.116	1.219	.226	-.959	3.999	.662	.130	.066	.327	3.062
	MPFIFlexibility	6.284	1.029	.554	6.104	<.001	4.237	8.330	.807	.548	.331	.357	2.797
	MPFIInflexibility	-.422	1.019	-.032	-.415	.679	-2.448	1.603	-.513	-.044	-.023	.482	2.073
	TotalFacit	.247	.085	.257	2.917	.004	.079	.415	.740	.299	.158	.379	2.638
	Gender Binary Variable	3.738	1.231	.174	3.035	.003	1.290	6.185	.029	.309	.165	.896	1.115

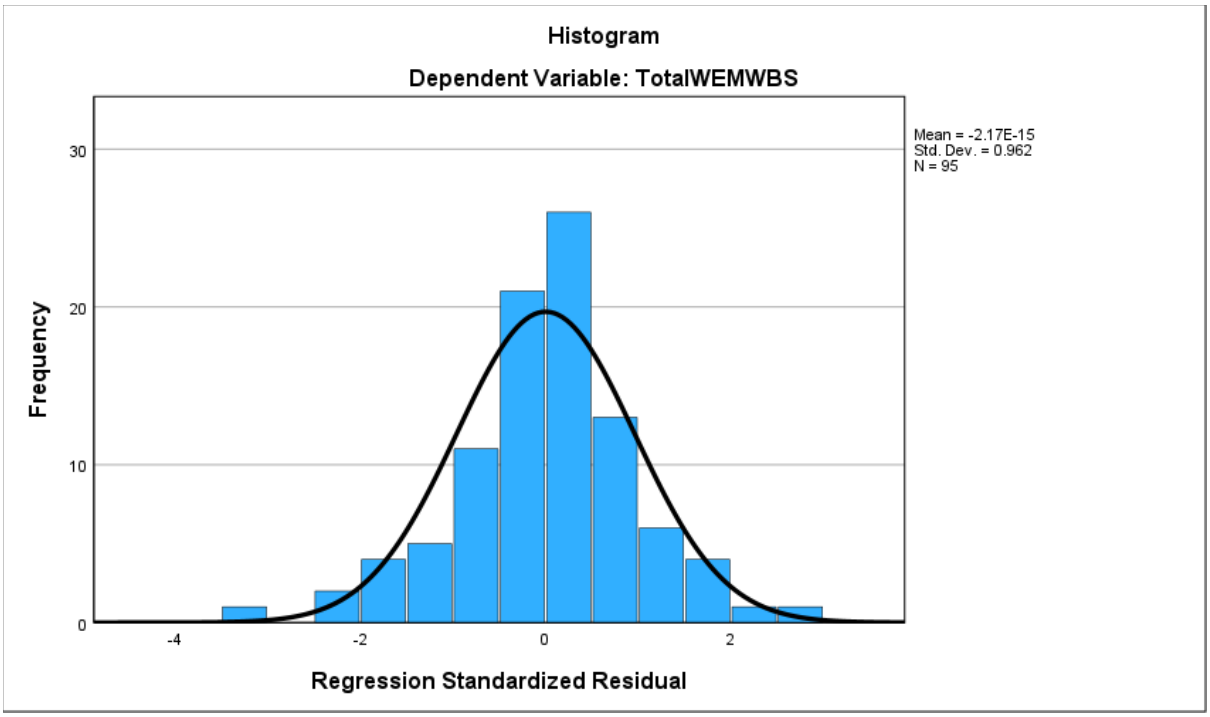
a. Dependent Variable: TotalWEMWBS

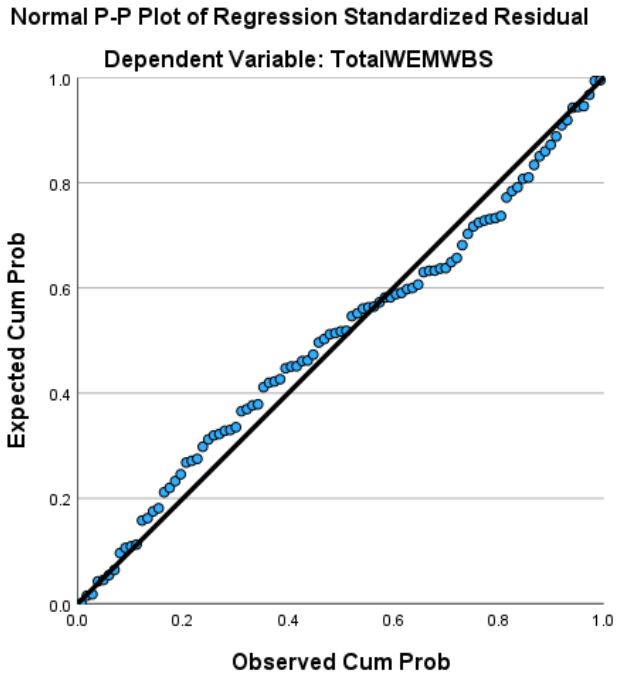
Correlations

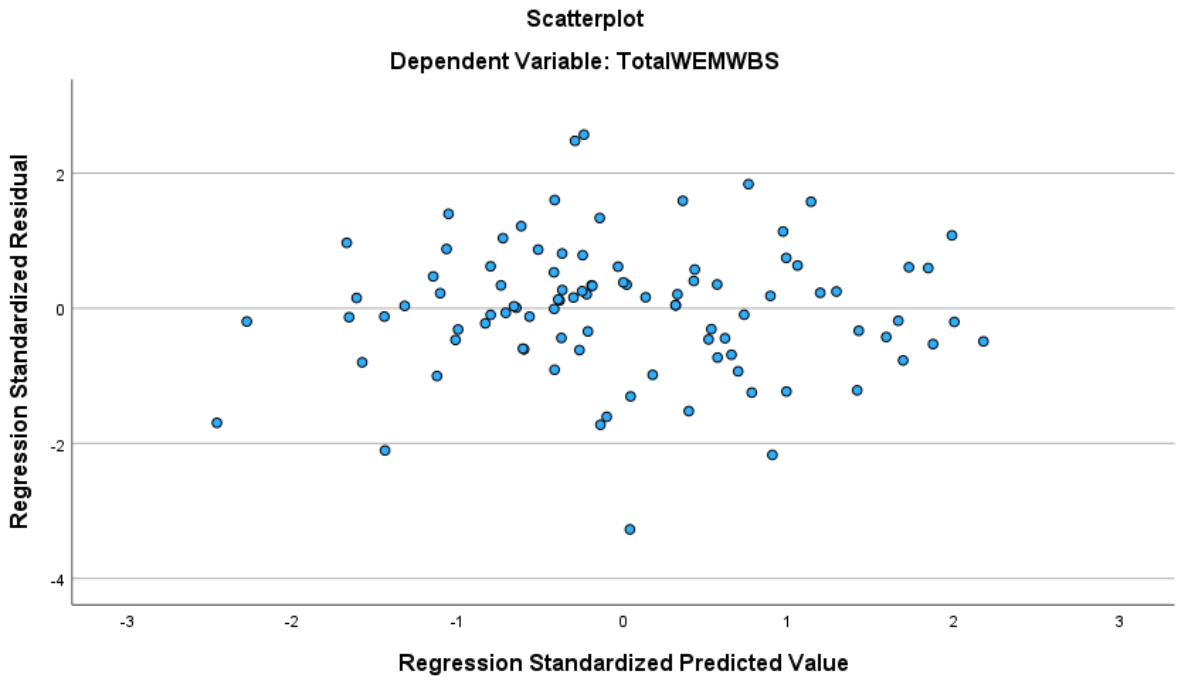
Correlations

		TotalWEMWBS	Q6AgeInYears	Q9TimeSinceDianosisInMonthsIV1	TotalSCSSFMean	MPFIFlexibility	MPFIInflexibility	TotalFacit	Gender Dummy Variable
Pearson Correlation	TotalWEMWBS	1.000	.242	.094	.662	.807	-.513	.740	.029
	Q6AgeInYears	.242	1.000	-.027	.290	.272	-.147	.235	.106
	Q9TimeSinceDianosisInMonthsIV1	.094	-.027	1.000	-.065	-.049	.057	.078	-.192
	TotalSCSSFMean	.662	.290	-.065	1.000	.676	-.711	.645	-.008
	MPFIFlexibility	.807	.272	-.049	.676	1.000	-.515	.752	-.130
	MPFIInflexibility	-.513	-.147	.057	-.711	-.515	1.000	-.454	-.046
	TotalFacit	.740	.235	.078	.645	.752	-.454	1.000	-.169
	Gender Dummy Variable	.029	.106	-.192	-.008	-.130	-.046	-.169	1.000
Sig. (1-tailed)	TotalWEMWBS	.	.009	.182	<.001	<.001	<.001	<.001	.390
	Q6AgeInYears	.009	.	.398	.002	.004	.078	.011	.153
	Q9TimeSinceDianosisInMonthsIV1	.182	.398	.	.267	.319	.293	.225	.031
	TotalSCSSFMean	.000	.002	.267	.	.000	.000	.000	.471
	MPFIFlexibility	.000	.004	.319	.000	.	.000	.000	.104
	MPFIInflexibility	.000	.078	.293	.000	.000	.	.000	.330
	TotalFacit	.000	.011	.225	.000	.000	.000	.	.051
	Gender Dummy Variable	.390	.153	.031	.471	.104	.330	.051	.
N	TotalWEMWBS	95	95	95	95	95	95	95	95
	Q6AgeInYears	95	95	95	95	95	95	95	95
	Q9TimeSinceDianosisInMonthsIV1	95	95	95	95	95	95	95	95
	TotalSCSSFMean	95	95	95	95	95	95	95	95
	MPFIFlexibility	95	95	95	95	95	95	95	95
	MPFIInflexibility	95	95	95	95	95	95	95	95
	TotalFacit	95	95	95	95	95	95	95	95
	Gender Dummy Variable	95	95	95	95	95	95	95	95

10.1 Model diagnostics – normal distribution, linearity, residuals distributed in homogeneous fashion


Histogram
Dependent Variable: TotalWEMWBS
Mean = -2.17E-15
Std. Dev. = 0.962
N = 95
Frequency
30
20
10
0
-4
-2
0
2
Regression Standardized Residual


Normal P-P Plot of Regression Standardized Residual
Dependent Variable: TotalWEMWBS
Expected Cum Prob
1.0
0.8
0.6
0.4
0.2
0.0
0.0
0.2
0.4
0.6
0.8
1.0
Observed Cum Prob



Appendix 11: Multiple regression analysis with SCS-SF two-factor scoring

Descriptive Statistics

	Mean	Std. Deviation	N
TotalWEMWBS	45.863157894736840	10.578591916833217	95
Q6AgeInYears	49.74	11.804	95
Q9TimeSinceDianosisInMonthsIV1	42.999	51.4360	95
SCSSFSelfKind	3.2053	.85416	95
SCSSFSelfCrit	2.7439	.98656	95
MPFIFlexibility	3.784210526315787	.932922808718651	95
MPFIInflexibility	3.104385964912282	.811410974209777	95
TotalFacit	25.19	11.013	95
Gender Binary Variable	.4000	.49250	95

Correlations

		Total WEMWBS	Q6AgeInYears	Q9TimeSinceDianosisInMonthsIV1	SCSSFSelfKind	SCSSFSelfCrit	MPFIFlexibility	MPFIInflexibility	TotalFacit	GenderBinaryVariable
Pearson Correlation	TotalWEMWBS	1.000	.242	.094	.738	.442	.807	-.513	.740	.029
	Q6AgeInYears	.242	1.000	-.027	.296	.218	.272	-.147	.235	.106
	Q9TimeSinceDianosisInMonthsIV1	.094	-.027	1.000	.029	-.131	-.049	.057	.078	-.192
	SCSSFSelfKind	.738	.296	.029	1.000	.529	.726	-.539	.658	-.050
	SCSSFSelfCrit	.442	.218	-.131	.529	1.000	.475	-.693	.483	.031

	MPFIFlexibility	.807	.272	-.049	.726	.475	1.000	-.515	.752	-.130
	MPFIInflexibility	-.513	-.147	.057	-.539	-.693	-.515	1.000	-.454	-.046
	TotalFacit	.740	.235	.078	.658	.483	.752	-.454	1.000	-.169
	Gender Binary Variable	.029	.106	-.192	-.050	.031	-.130	-.046	-.169	1.000
Sig. (1-tailed)	TotalWEMWBS	.	.009	.182	<.001	<.001	<.001	<.001	<.001	.390
	Q6AgeInYears	.009	.	.398	.002	.017	.004	.078	.011	.153
	Q9TimeSinceDianosisInMonthsIV1	.182	.398	.	.390	.103	.319	.293	.225	.031
	SCSSFSelfKind	.000	.002	.390	.	.000	.000	.000	.000	.316

	SCSSFSelfCrit	.000	.017	.103	.000	.	.000	.000	.000	.384
	MPFIFlexibility	.000	.004	.319	.000	.000	.	.000	.000	.104
	MPFIInflexibility	.000	.078	.293	.000	.000	.000	.	.000	.330
	TotalFacit	.000	.011	.225	.000	.000	.000	.000	.	.051
	Gender Binary Variable	.390	.153	.031	.316	.384	.104	.330	.051	.
N	TotalWEMWBS	95	95	95	95	95	95	95	95	95
	Q6AgeInYears	95	95	95	95	95	95	95	95	95
	Q9TimeSinceDianosisInMonthsIV1	95	95	95	95	95	95	95	95	95
	SCSSFSelfKind	95	95	95	95	95	95	95	95	95
	SCSSFSelfCrit	95	95	95	95	95	95	95	95	95
	MPFIFlexibility	95	95	95	95	95	95	95	95	95
	MPFIInflexibility	95	95	95	95	95	95	95	95	95

	TotalFacit	95	95	95	95	95	95	95	95	95
	Gender Binary Variable	95	95	95	95	95	95	95	95	95

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
					R Square Change	F Change	df1	df2	Sig. F Change	
1	.873[a]	.762	.739	5.399354229418712	.762	34.353	8	86	<.001	1.669

a. Predictors: (Constant), Gender Binary Variable, SCSSFSelfCrit, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, MPFIFlexibility, MPFIInflexibility, SCSSFSelfKind, TotalFacit

b. Dependent Variable: TotalWEMWBS

ANOVA[a]

Model	Sum of Squares	df	Mean Square	F	Sig.

1	Regression	8012.061	8	1001.508	34.353	<.001[b]
	Residual	2507.160	86	29.153		
	Total	10519.221	94			

a. Dependent Variable: TotalWEMWBS

b. Predictors: (Constant), Gender Binary Variable, SCSSFSelfCrit, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, MPFIFlexibility, MPFIInflexibility, SCSSFSelfKind, TotalFacit

Coefficients[a]

Model	Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
	B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1 (Constant)	13.934	6.225		2.238	.028	1.559	26.309					

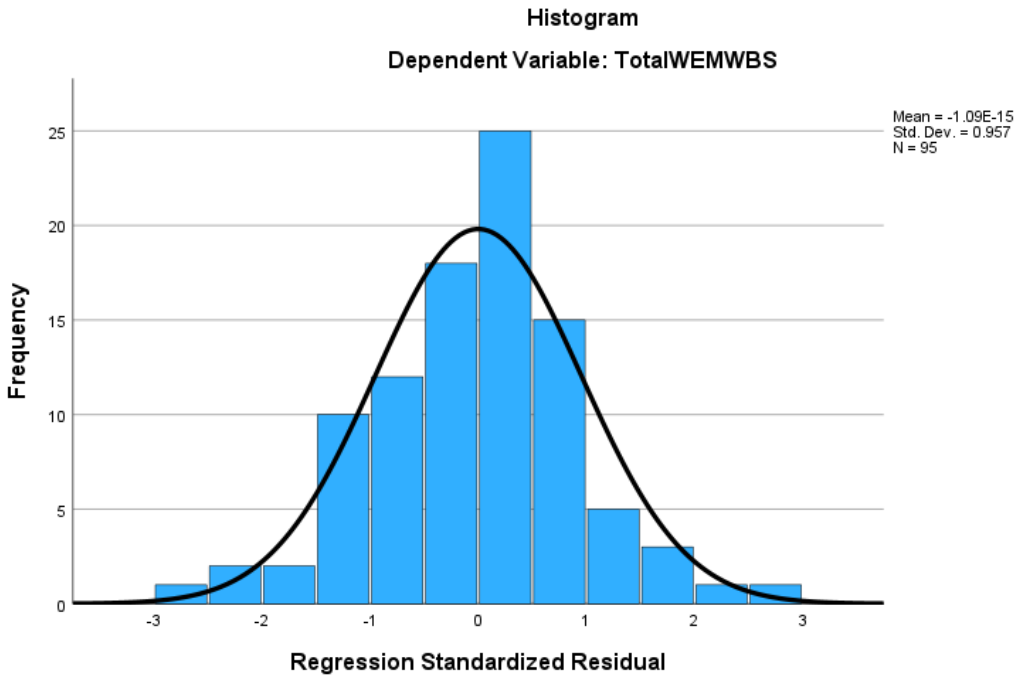
Q6AgeInYears	-.025	.050	-.027	-.489	.626	-.125	.076	.242	-.053	-.026	.876	1.141
Q9TimeSinceDianosisInMonthsIV1	.024	.011	.118	2.129	.036	.002	.047	.094	.224	.112	.900	1.112
SCSSFSelfKind	2.915	1.040	.235	2.803	.006	.848	4.983	.738	.289	.148	.393	2.544
SCSSFSelfCrit	-.716	.837	-.067	-.855	.395	-2.381	.949	.442	-.092	-.045	.454	2.201
MPFIFlexibility	5.371	1.061	.474	5.063	<.001	3.262	7.479	.807	.479	.267	.317	3.158
MPFIInflexibility	-1.010	1.015	-.077	-.995	.322	-3.028	1.007	-.513	-.107	-.052	.457	2.186
TotalFacit	.242	.082	.252	2.942	.004	.078	.405	.740	.302	.155	.379	2.639
Gender Binary Variable	3.633	1.195	.169	3.040	.003	1.257	6.008	.029	.311	.160	.895	1.117

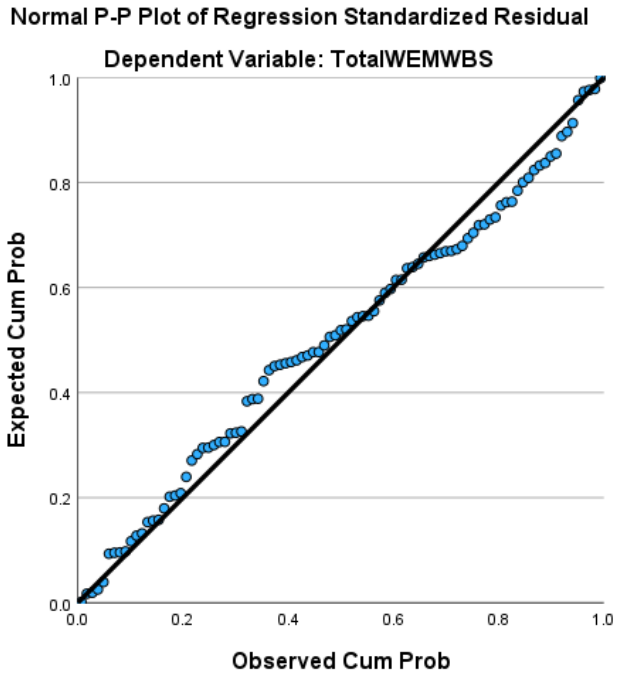
a. Dependent Variable: TotalWEMWBS

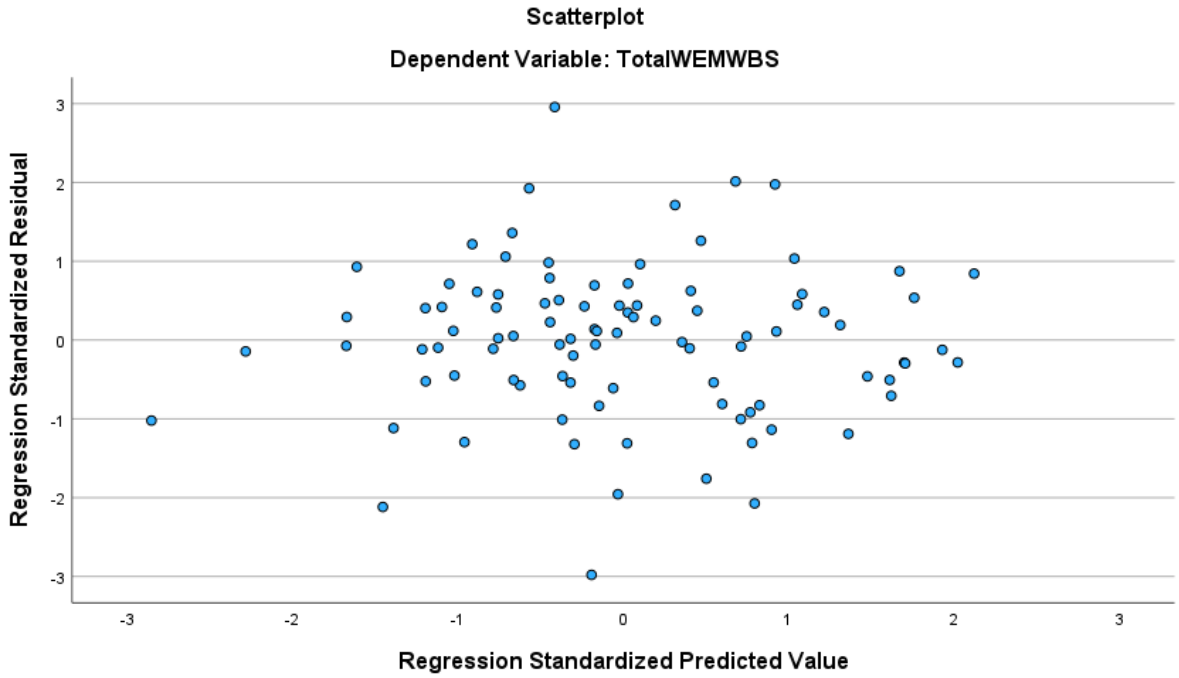
Casewise Diagnostics[a]

Case Number	Std. Residual	TotalWEMWBS	Predicted Value	Residual
1	2.957	58.000000000000000	42.034245837994725	15.965754162005268
9	-2.980	28.000000000000000	44.090696718714660	-16.090696718714668
64	2.013	63.000000000000000	52.129905200419245	10.870094799580748
68	-2.073	42.000000000000000	53.194513773114814	-11.194513773114814
87	-2.118	21.000000000000000	32.438385254821220	-11.438385254821220

a. Dependent Variable: TotalWEMWBS


Histogram
Dependent Variable: TotalWEMWBS
Mean = -1.09E-15
Std. Dev. = 0.957
N = 95
Frequency
Regression Standardized Residual


Normal P-P Plot of Regression Standardized Residual
Dependent Variable: TotalWEMWBS
Expected Cum Prob
Observed Cum Prob

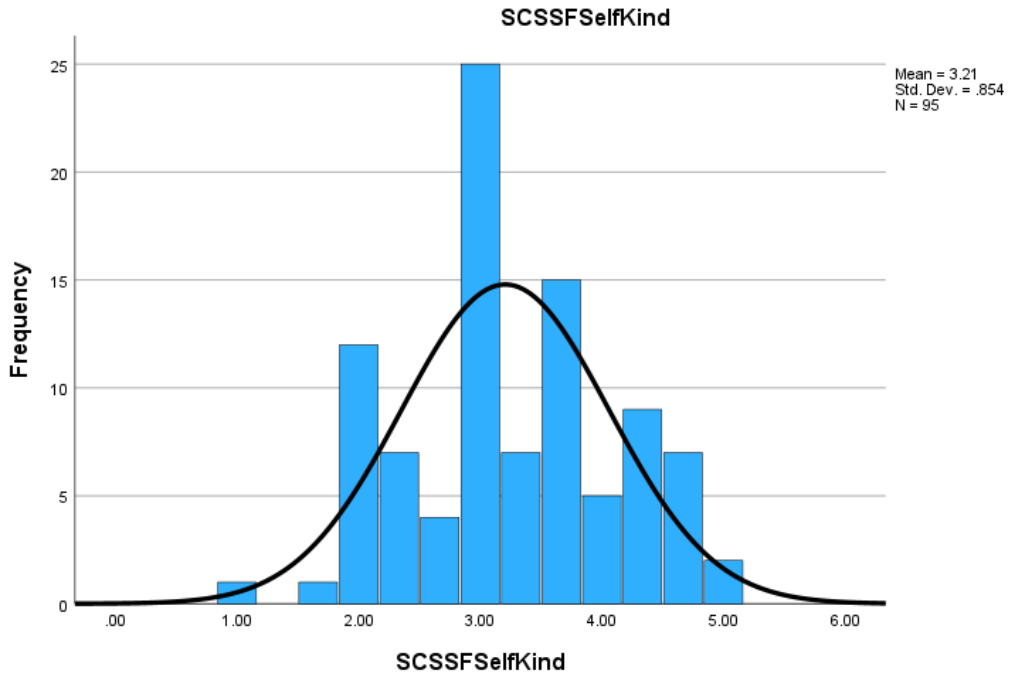


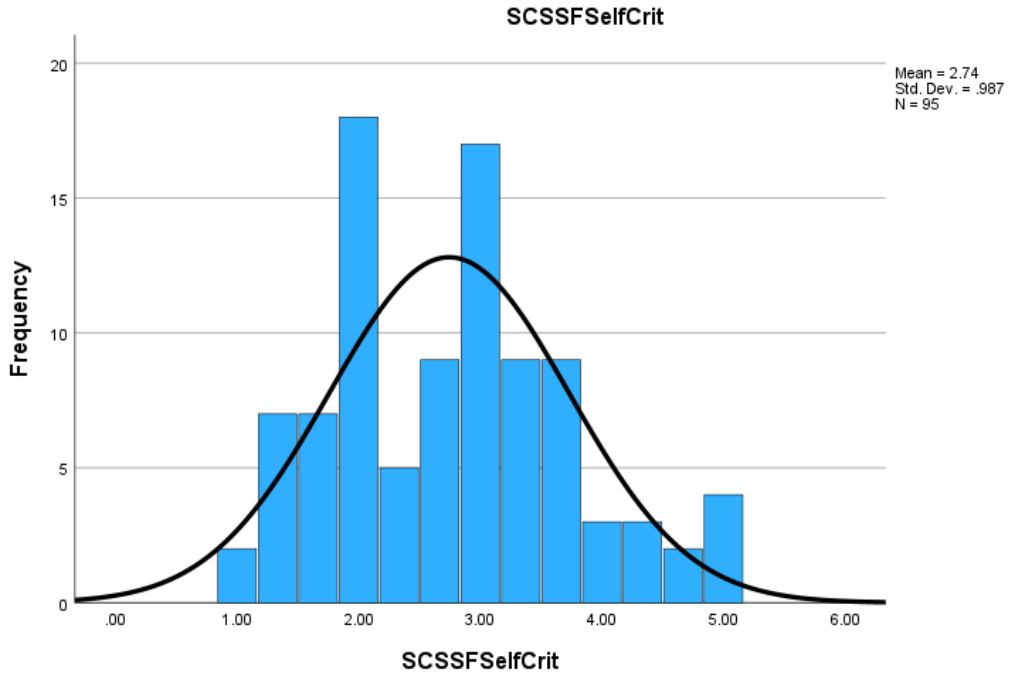
11.1: Descriptives of SCS-SF two-factor scores

Statistics

		SCSSFSelfKind	SCSSFSelfCrit
N	Valid	95	95
	Missing	0	0
Mean		3.2053	2.7439

Median	3.1667	2.6667
Mode	2.83	3.33
Std. Deviation	.85416	.98656
Skewness	-.020	.297
Std. Error of Skewness	.247	.247
Kurtosis	-.535	-.378
Std. Error of Kurtosis	.490	.490
Range	4.00	4.00





Appendix 12: Re-running the model without inflexibility

Model Summary[b]

R				Change Statistics	

Model		R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	F Change	df 1	df 2	Sig. F Change	Durbin-Watson
1	.862[a]	.743	.726	5.540885648138866	.743	42.438	6	88	<.001	1.666

a. Predictors: (Constant), Gender Binary Variable, TotalSCSSFMean, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, TotalFacit, MPFIFlexibility

b. Dependent Variable: TotalWEMWBS

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	7817.497	6	1302.916	42.438	<.001[b]
	Residual	2701.724	88	30.701		
	Total	10519.221	94			

a. Dependent Variable: TotalWEMWBS

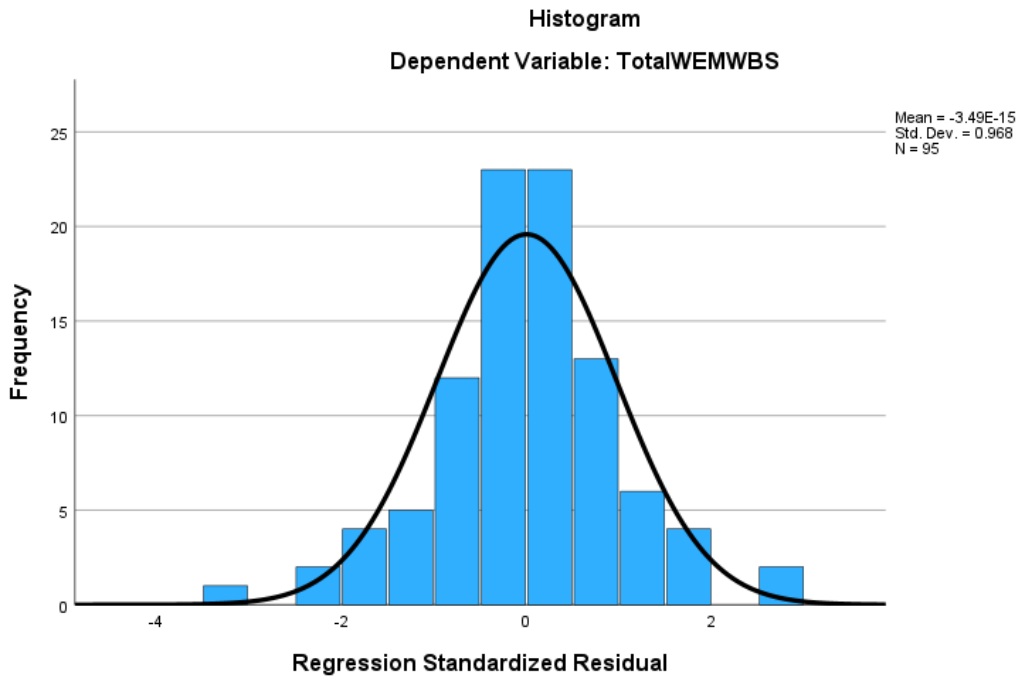
b. Predictors: (Constant), Gender Binary Variable, TotalSCSSFMean, Q9TimeSinceDianosisInMonthsIV1, Q6AgeInYears, TotalFacit, MPFIFlexibility

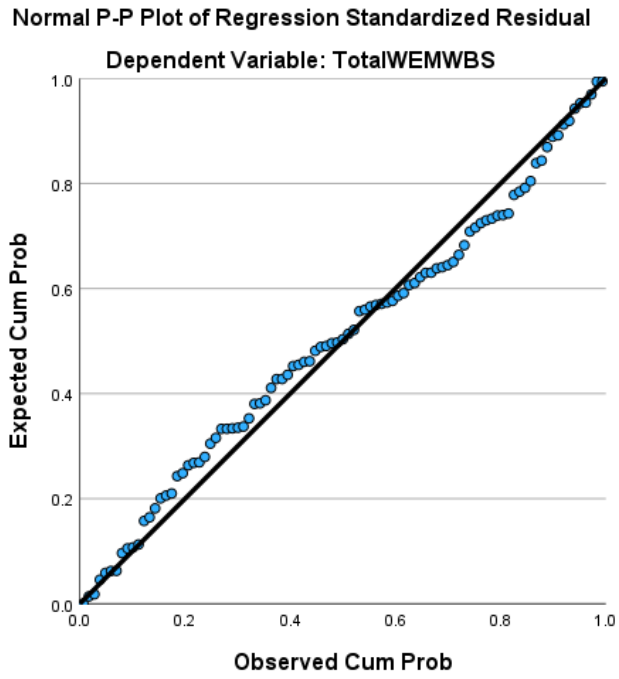
Coefficients[a]

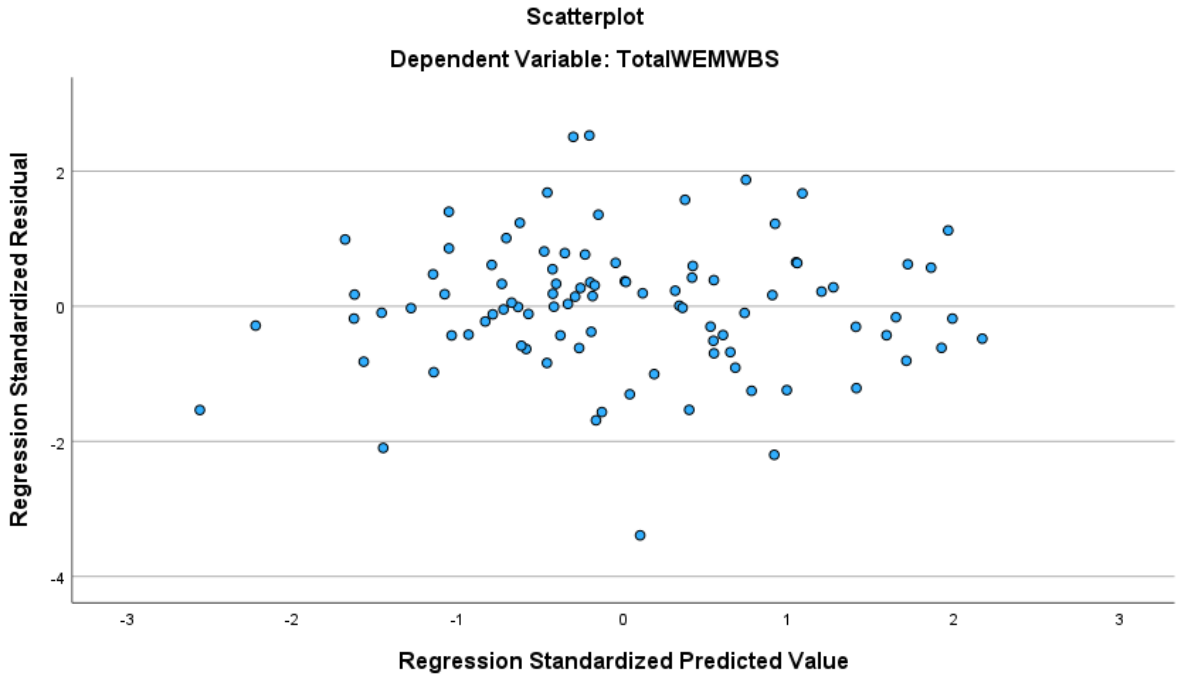
Model	Unstandardized Coefficients		Standardized Coefficients			95.0% Confidence Interval for B		Correlations			Collinearity Statistics	
	B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part	Tolerance	VIF
1 (Constant)	8.674	3.331		2.604	.011	2.055	15.294					
Q6AgeInYears	-.022	.051	-.025	-.435	.664	-.124	.080	.242	-.046	-.024	.888	1.126
Q9TimeSinceDianosisInMonthsIV1	.030	.012	.143	2.560	.012	.007	.052	.094	.263	.138	.929	1.076
TotalSCSSFMean	1.812	1.025	.138	1.768	.080	-.224	3.848	.662	.185	.096	.479	2.086

MPFIFlexibility	6.327	1.019	.558	6.208	<.001	4.302	8.353	.807	.552	.335	.361	2.768
TotalFacit	.246	.084	.256	2.916	.004	.078	.413	.740	.297	.158	.380	2.633
Gender Binary Variable	3.785	1.220	.176	3.102	.003	1.360	6.210	.029	.314	.168	.904	1.106

a. Dependent Variable: TotalWEMWBS



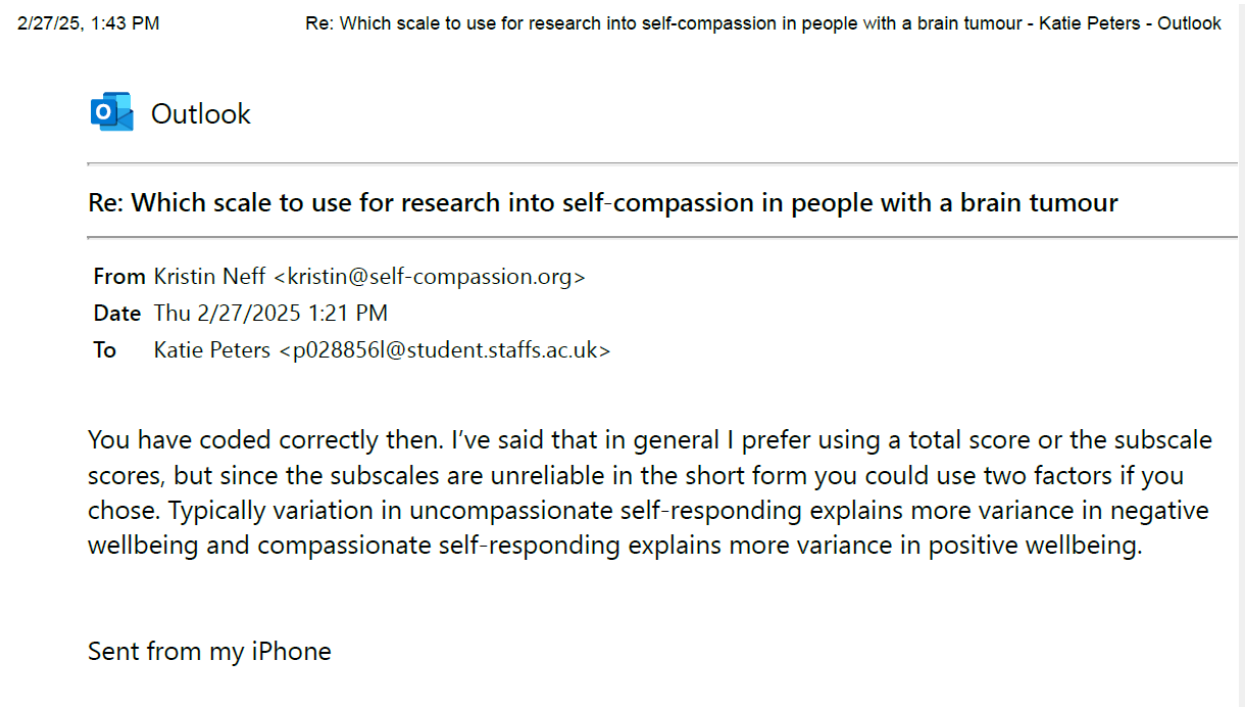

Normal P-P Plot of Regression Standardized Residual
Dependent Variable: TotalWEMWBS
Expected Cum Prob
Observed Cum Prob
0.0
0.2
0.4
0.6
0.8
1.0


Scatterplot
Dependent Variable: TotalWEMWBS
Regression Standardized Residual
Regression Standardized Predicted Value
2
0
-2
-4
-3
-2
-1
0
1
2
3

Appendix 13: Author guidelines

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=pnrh20#words

Appendix 14: Email with Kristen Neff re: scoring SCSSF



2/27/25, 1:43 PM Re: Which scale to use for research into self-compassion in people with a brain tumour - Katie Peters - Outlook

Outlook

Re: Which scale to use for research into self-compassion in people with a brain tumour

From Kristin Neff <kristin@self-compassion.org>
Date Thu 2/27/2025 1:21 PM
To Katie Peters <p028856l@student.staffs.ac.uk>

You have coded correctly then. I've said that in general I prefer using a total score or the subscale scores, but since the subscales are unreliable in the short form you could use two factors if you chose. Typically variation in uncompassionate self-responding explains more variance in negative wellbeing and compassionate self-responding explains more variance in positive wellbeing.

Sent from my iPhone

Paper 3: Executive Summary

What contributes to wellbeing in people with a primary malignant brain tumour*?:

An executive summary

*PMBT; a cancerous tumour that started in the brain.

Word Count: 2472

This paper was written with the support of two of the research participants, Lucy Green Malabuna and Tansi Lee, and Adam Thomson at Brainstrust. Thank you.

This paper

This report summarises research conducted on psychological factors that might contribute to wellbeing for UK adults (18+) living with a Primary Malignant Brain Tumour (PMBT; a cancerous brain tumour originating in the brain).

Wellbeing:

"Feeling good and functioning well"
(Tennant et al., 2007)

It is important to understand what contributes to wellbeing in people with PMBT to know how to improve it. Research into other cancers has shown the following are connected to improved wellbeing:

Psychological Flexibility

Tolerating, not avoiding, distress. Living in line with values.

Time-since diagnosis

How long has elapsed since finding out about PMBT.

Self-compassion

Being kind to yourself.

Spirituality

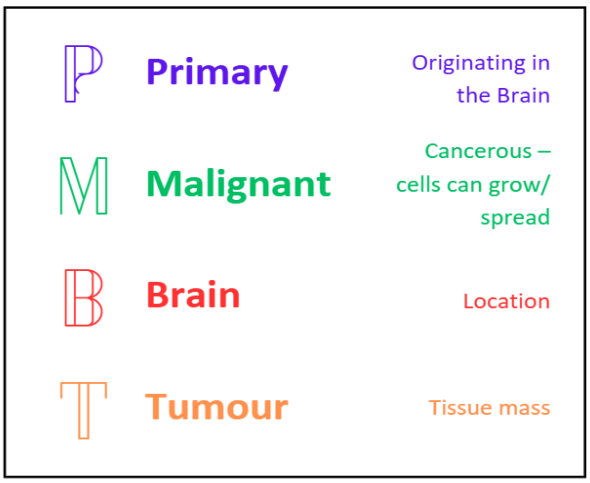
Finding meaning and purpose in life

This research hoped to find out if these are important to wellbeing in PMBT. If so, they can be targeted through practices and therapies. The study was approved by the University of Staffordshire ethics committee.

This report has been written for people with PMBT and anyone supporting them (family, friends, and healthcare professionals, particularly clinical psychologists). All participants were asked if they wanted to contribute to this summary (Appendix 1). Nine responded to a survey about how they wanted results shared (Appendix 2) and two contributed to this report.

Background: Why was this research conducted?

The impact of living with a Primary Malignant Brain Tumour (PMBT)



'**P M B T**' is not used among patients and professionals because PMBT are referred to by their name (for example, astrocytoma, oligodendroglioma, glioblastoma). PMBT is used in this report to refer to all types of primary malignant brain tumours.

PMBT are rare; the 9th most common cancer (Cancer Research UK, 2024). Being diagnosed with a PMBT can be scary (Goebel et al., 2010), probably because it is associated with both lower survival rates than other cancers (Nuffield Trust, 2024) and significant changes to personality, emotions, behaviour, and quality of life (Ownsworth, 2016). The impact of PMBT

depends on its location, variant, and size (Louis et al., 2021; Trad et al., 2015). Symptoms and treatment side-effects include pain, headaches, seizures, vomiting, sleep difficulties, thinking, planning and memory problems (cognitive impairments), and visual and motor impairments (Acquaye et al., 2019; Chieffo et al., 2023). PMBT can therefore also impact independence (Dutta et al., 2009).

Wellbeing

Quality of life and emotional health are affected by the impacts of PMBT. 'Wellbeing' is a term capturing both quality of life and emotional health. In other studies, wellbeing has been linked to having a better overall experience of living with cancer (Khalili, Bahrami & Ashouri, 2021). Moreover, not everyone living with cancer experiences worsened wellbeing (Ciarrochi, Fisher & Lane, 2011). What makes two people with the same diagnosis experience different levels of wellbeing is interesting. If we can understand what contributes to wellbeing, we might be able to improve it. The following have been found to support wellbeing in other cancers:

Psychological flexibility

Psychological flexibility is the process of allowing rather than avoiding difficult experiences, like symptoms. It involves doing things that are important to you (values) whilst living with challenges (Hayes et al., 2006). For ease, this construct will be referred to as '**flexibility'**.

Self-compassion

Self-compassion involves three things: knowing that you are experiencing difficulties (mindfulness); understanding this is part of life (common humanity); and, offering kindness to yourself (self-kindness) (Neff, 2003).

Spirituality

'Spirituality' is a '*personal connection with something that promotes meaning and personal growth*' (deBrito Sena et al., 2021). Spirituality might be important for wellbeing among people with PMBT as they face major life changes and worse outcomes compared to other cancers (Watanabe & MacLeod, 2005). One participant consulted when planning this study said spirituality was crucial for their wellbeing whilst living with PMBT.

Time-since diagnosis

Another study found quality of life improved as time increased since diagnosis of Glioblastoma (Palmer et al., 2021). The current study wanted to see if this was the case with PMBT. Whilst time is not something that can be changed, the findings would be useful for understanding at what point wellbeing interventions would be most helpful.

Age and Gender

Age and gender are often included in studies like this to determine whether they influence outcomes. They were considered in the study, along with the factors described above, to see if they impact wellbeing. If not, it tells us the other factors influence wellbeing *regardless* of age and gender.

Why carry out this research?

To the author's knowledge, this is the first study to examine these factors in PMBT specifically. There are a few reasons for this. Often, people with cognitive impairment are not eligible to participate in research due to difficulties in reading, understanding, and answering questions. People with PMBT may have been excluded from other studies due to potential cognitive impairments. Secondly, previous research on brain tumours group cancerous, benign/non-malignant, secondary, and primary together (Baker et al., 2016). However, the impact of brain tumours differs. People with primary brain tumours experience more psychological challenges than those with secondary (Ostgathe et al., 2009). People with malignant brain tumours report higher distress than those with non-malignant (Fehrenbach et al., 2021). It is thus advised to investigate each type separately (Taphoorn, Sizoo & Bottomley, 2010).

Aim of the study

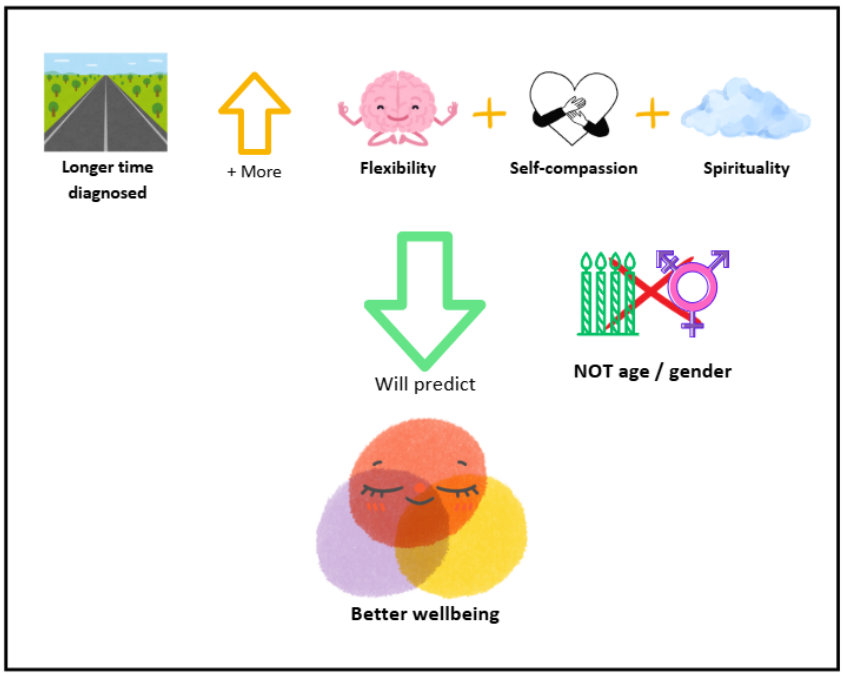
The aim of this study was to investigate whether time-since diagnosis, flexibility, self-compassion, and spirituality **predict** wellbeing in participants with PMBT regardless of age and gender.

How can you 'predict' wellbeing?

This type of research uses a large number of responses on questionnaires about the factors of interest to see if the answers accurately calculate the answers to the wellbeing questions.

What was predicted to happen?

It was hypothesised, due to previous research on these topics, that a longer time-since diagnosis and higher levels of flexibility, self-compassion, and spirituality will predict higher wellbeing regardless of age and gender.



Methods: How the research was carried out

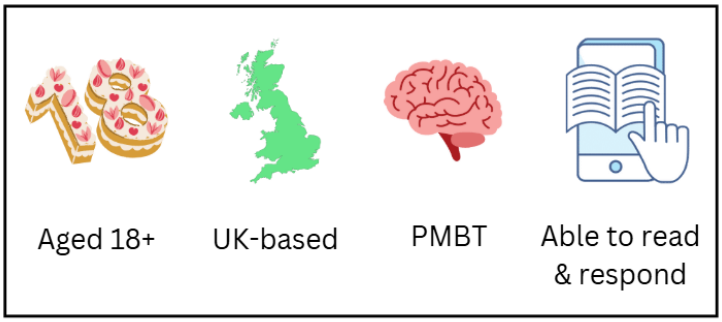
How were people informed of the study?

Potential participants were recruited through social media and charities between January 2024 and January 2025.

Who could take part?

Anyone:

- Over 18 years old
- Living in the UK
- With a diagnosis of PMBT
- Able to read, understand and answer the questions.



What did they have to do?

This study was a cross-sectional design, which means data was collected at a single timepoint through a survey made up of five shorter questionnaires:

- **Demographics**

This included questions on age, gender and time-since diagnosis.

- **Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) (Tennant et al., 2007)**

WEMWBS has 14 questions to measure wellbeing. Questions include 'I've been feeling relaxed' and 'I've been feeling close to other people', which participants rate on a 5-point scale from 1 (none of the time) to 5 (all of the time) when thinking about the previous two weeks.

- **Multidimensional Psychological Flexibility Inventory-24 (MPFI-24) (Rolffs, Rogge & Wilson, 2016).**

MPFI-24 has 24 questions measuring psychological flexibility and inflexibility with two separate scores. Participants answer on a 6-point scale how often in the past two weeks they, for example, 'tried to make peace with my negative thoughts and feelings rather than resisting them' or 'let negative feelings come and go without getting caught up in them'. A participant said these questions were 'very triggering and challenging but very correct indeed'.

- **Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being (FACIT-Sp-12) (Peterman et al., 2002)**

FACIT-Sp-12 has 12 questions about spiritual wellbeing whilst living with an illness. Questions include, 'I am able to reach down deep into myself for comfort' and 'I know that whatever happens with my illness, things will be okay'. Participants rate their responses 0 (not at all) to 4 (very much). One participant expressed being asked these questions 'moved' them 'to tears' in a positive way.

- **Self-compassion scale short-form (SCS-SF) (Raes et al., 2011)**

This has 12 questions and a 5-point Likert scale ranging from 1 (almost never) to 5 (almost always). Questions include 'When I'm going through a very hard time, I give myself the caring and tenderness I need' and 'When I'm feeling down, I tend to obsess and fixate on everything that's wrong'.

How do answers to these questionnaires tell us what we want to know?

The answers to the questionnaires are input into a statistical database, where we can run a statistical analysis called a multiple regression. It shows which factors have the biggest impact on wellbeing. Age and gender were included as predictor variables to see if they affect wellbeing too.

A Multiple Regression tells us: 

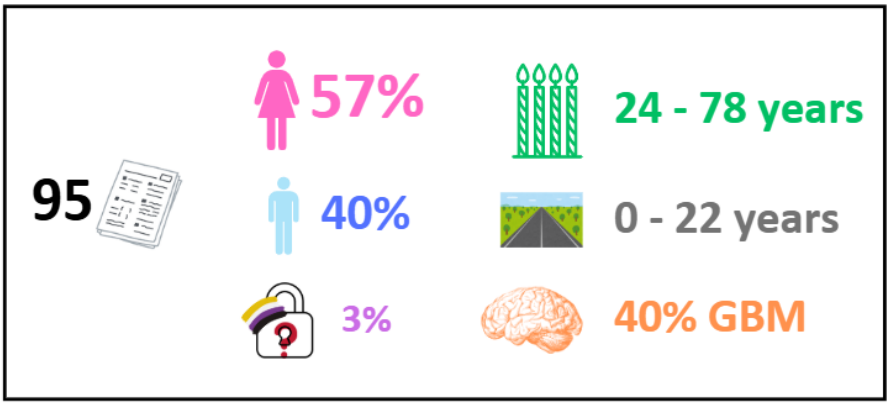
How different factors, 'predictor variables' (flexibility, spirituality, self-compassion, time-since diagnosis), work together to affect the outcome or 'dependent variable' (wellbeing).

The regression shows which variables are 'significant predictors' of wellbeing. This means they are strongly involved in forecasting the wellbeing scores.

Who took part?

Ninety-five UK adults with PMBT completed the questionnaires. More participants (57%) were female than male. Age ranged from 24-78 years with 37 and 53 years being the most

reported ages. Time-since diagnosis ranged from 0–264 months (22 years) with most reporting 30-33 months (2.5 years). Most of the sample (40%) reported a diagnosis of GBM.



Key findings

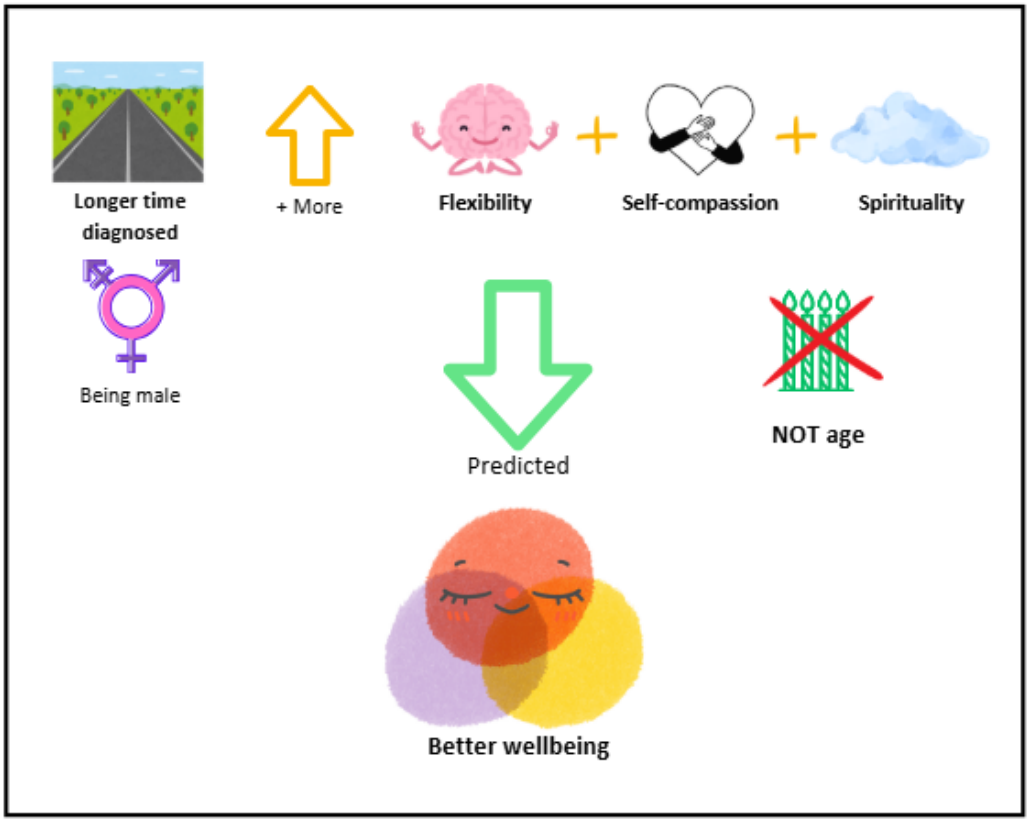
What were the main predictors of wellbeing?

The author's prediction was partially correct, and in line with previous studies:

- ✓ Flexibility, spirituality, self-compassion and time-since diagnosis were significant predictors of wellbeing.
- ✓ These results held, regardless of age.

To the author's surprise:

- Gender was the second most significant predictor of wellbeing. Being male predicted higher wellbeing scores.



What else was learnt?

All factors were found to be highly correlated to each other and to wellbeing. This means for example, higher levels of flexibility were related to higher levels of wellbeing; higher spirituality was related to higher self-compassion; and time-since diagnosis was related to gender (i.e. a longer time since diagnosis was related to being male). This confirms wellbeing as a concept comprises multiple components (Tennant et al., 2007).

What does this mean?

If flexibility, spirituality, and self-compassion are important to wellbeing in people with PMBT, psychological support could focus on improving these.

How can we do this?

- ***Acceptance and Commitment Therapy (ACT)*** is a type of psychological therapy which gives people ways to improve ***flexibility*** (Hulbert-Williams, Storey & Wilson, 2015).
    - It has been shown to support wellbeing in other cancer populations and more recently in populations where the brain is impacted, like dementia, brain injury, and motor neurones disease (Ambridge, Fleming & Henshall 2020; Craig et al., 2018; Gould et al., 2024).
- As ***spirituality*** includes lots of things, interventions targeting this are wide-ranging and can be quite creative.
    - For example, ***Dignity Therapy*** aimed to improve meaning and purpose in palliative care patients. It was found to improve depression and anxiety in a large cancer sample in which 4 participants had glioblastoma (Julião et al., 2014).
    - Group ***Reminiscence Therapy*** where people shared meaningful memories had positive results in a malignant and non-malignant brain tumour sample (Zhao, 2021).
    - ***MAST*** and ***CALM*** programmes offering both psychological and spiritual therapeutic support, and an online ***meditation*** course have produced positive results on wellbeing in samples including participants with PMBT (Jones,

Ownsworth & Shum; 2015; Loughan et al., 2022; Milbury et al., 2020; Ownsworth et al., 2022; Ownsworth et al., 2023).

- ***Compassion-Focussed Therapy*** (Gilbert, 2009) and ***Mindful Self- Compassion*** (Germer & Neff, 2019) are interventions and practices which foster ***self-compassion***.
    - They have both been shown in other cancer populations to be successful. As self-compassion was important to wellbeing in this PMBT sample, it is worth giving these interventions a try.

N.B. Some of these approaches can be done by yourself. See the resources section at the end.

Adaptations

Whilst these factors were important regardless of age, age should still be taken into account. Adapted versions of these interventions have been researched previously (e.g. Yee Wong's 2019 spirituality and aging support groups; Scarlora et al. 's 2022 adolescent spiritualty intervention; Gould et al.'s 2022 ACT for older adults; and, Airdrie's 2022 ACT for younger adults with PMBT).

What about the things we can't control, like time-since diagnosis and gender?

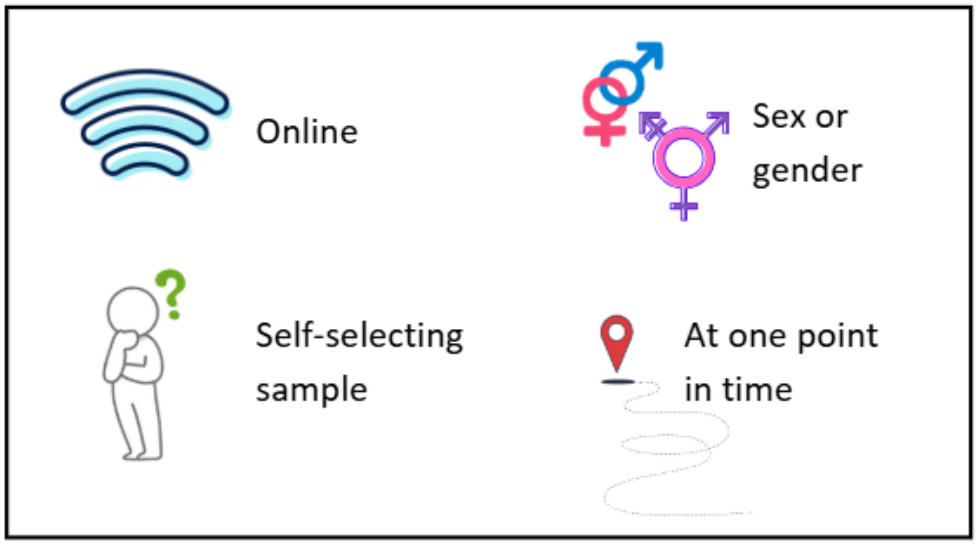
Timely intervention

Previous research has found that diagnosis is the most distressing part for people with PMBT (Goebel, von Harscher & Mehdorn, 2010). As this study found a longer time-since diagnosis predicted better wellbeing, these results could point to offering wellbeing support closer to diagnosis of PMBT.

Gender

The study did not gather enough information to understand why males had better wellbeing. Possibly because the study only collected information on self-identified gender not biological sex assigned at birth, which are different things. This finding could relate to the correlation with time-since diagnosis. If male participants reported a longer time-since diagnosis, and greater time-since diagnosis is related to wellbeing, this might be why males reported better wellbeing. Some cancer studies have found gender differences in coping styles, but this research is mixed (Zhou et al., 2023). It could also be that men do not accurately report emotional symptoms, to fit with how society expects them to be (Chatman 2020). Whilst it's unknown *how* gender impacted wellbeing in this study, it is important to consider gender differences in how people with PMBT experience and express wellbeing.

Study limitations and future research



- Whilst a few charity groups were visited, advertising was mainly on social media so those without internet may not have found out about it.
- There was no way of checking if participants were over 18, living in the UK and diagnosed with PMBT. However, there was nothing to gain from taking part (e.g. no monetary voucher provided) so it is unlikely people not meeting criteria got involved. Future studies could do the survey in person to avoid these first two limitations.
- There are a number of variables to consider relevant to gender (e.g., whether gender is associated with different response tendencies on measures and allowing for non-binary self-identification). Other variables could also be influencing outcomes, such as race, ethnicity, treatments, employment and income, coping styles, etc. Oncologist communication, charity support, and diet were other important factors suggested by one participant. As such, future research might include a broader array of variables.
- Information about the studied factors was taken at one time-point (the day the questionnaire was completed) which might affect results. A regression also does not tell us whether these factors *caused* wellbeing or vice versa. To better understand wellbeing in PMBT a study following the same people longitudinally, collecting information at different time-points, is best. Relatedly, an experimental study assessing the effectiveness of the suggested interventions would be interesting (e.g., using control and treatment groups).

Conclusion

The current study helps understand wellbeing in an under-researched cancer population who face physical, emotional, functional, and cognitive impacts. It showed flexibility, spirituality, self-compassion, and gender impact wellbeing. This implies it might be helpful to bolster flexibility, spirituality, and self-compassion, closer to diagnosis, as part of an overall approach to supporting individuals with PMBT. Further research would be necessary to clarify gender differences and how effective these strategies are in enhancing wellbeing.

Dissemination

These findings will be shared through the same means the study was advertised (social media and charities) and with healthcare professionals. It will also be submitted for publication to "Journal of Neuropsychological Rehabilitation".

Resources

These free resources offer more information about the psychological factors found to influence wellbeing in this study and practices to improve them:

Psychological Flexibility

https://www.actmindfully.com.au/free-stuff/

https://thehappinesstrap.com/free-resources/

https://www.getselfhelp.co.uk/act-acceptance-commitment-therapy/

Self-compassion

https://balancedminds.com/compassion-focused-therapy-resources/

https://www.worldofbooks.com/en-gb/products/compassionate-mind-book-paul-gilbert-9781849010986

https://self-compassion.org/books-by-kristin-neff/

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Appendices

Appendix 1: Email to participants about involvement

Re: Executive summary support

Hi there,

You are receiving this email because you left your contact details on my questionnaire about wellbeing in people with a primary malignant brain tumour. Thank you so much for this.

I have now closed the survey, completed the analysis and written up the results in an 8000 word report that is submitted to my university for my Doctoral qualification in Clinical Psychology (a training to become a Clinical Psychologist).

I'd love to know how you would like to results to be shared - a podcast, webinar, video... Or something else!
Please share your ideas here:
https://staffordshire.qualtrics.com/jfe/form/SV_eF3unMg0HiHJBgW

Would you like to help more?

I need to write an accessible summary of the report. For this, I would love the input of those for whom the results apply. This would involve reading and commenting on a 2500-word summary of the longer report, within the space of a few weeks, so please only accept if you feel able.

I have had an overwhelming response, which is fantastic, but I sadly won't be able to consult everyone for the report, so I will need to only accept the first five people who reply.

Please reply if you would like to help with reading and giving your thoughts on the 2500 word written report.

Many thanks,

Appendix 2: How participants wanted to receive results of the study