

THE UNIVERSITY OF HULL

Professionals' Diagnostic and Prognostic Communication Practices In
Cancer, and the Mediating Effect of Illness Perceptions on Quality of Life in
Brain Tumour Patients

being a Thesis submitted in partial fulfilment
of the requirements for the degree of Doctor of Clinical Psychology

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by

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This thesis is dedicated to the memory of Patricia Evans, who would have been so proud.

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Overview:

The portfolio has three parts. Part one is a systematic literature review, in which the empirical literature relating to general disclosure practices of clinicians regarding the diagnosis and prognosis of cancer is reviewed. Part two is an empirical paper, which explores the potential mediating effect of illness perceptions on the relationship between diagnosis communication and quality-of-life in people with a brain tumour. Part three comprises the appendices.

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Part One: Systematic Literature Review

This Paper is written in the format ready for submission to the
International Journal of Clinical Practice.

See Appendix B for submission guidelines.

A Systematic Literature Review of the General Practice of Clinicians For Disclosing Diagnostic and Prognostic Information In Cancer.

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Abstract

Background: Oncology patients have expressed the wish to be informed of diagnostic and prognostic information in an open and timely manner. The positive outcomes of having these discussions has been researched, both in relation to patients and their caregivers. Investigations of clinicians' personal opinions about disclosure have revealed the majority believe patients should be told their diagnosis. However, historically it has not always been the case that clinicians disclose this information in practice. *Procedure:* A systematic literature search was conducted, and the relevant data was extracted and presented using a narrative synthesis approach. *Participants:* 3479 qualified clinicians with a range of specialities working with oncology patients were included in this review. *Findings:* This review suggests clinicians do not consistently disclose diagnosis and prognosis to cancer patients, which stands in conflict with patient preferences and service guidelines. There is an apparent difference between clinicians' opinion and their clinical practice, with more clinicians believing the diagnosis and prognosis should be disclosed in comparison to their reported practice. A vast array of factors contributed to clinicians' disclosure practices, but due to a high level of inconsistency, general disclosure practices cannot be attributed to any consistent clinician, personal, or patient factors alone. *Conclusions:* Not all clinicians report they routinely disclose diagnostic and prognostic information to patients, and there are a number of factors they consider when making this decision. More should be done within services to increase disclosure rates to bring this in line with patient preferences and current guidelines.

Review Criteria

Literature in this review was gathered from a systematic search of databases relevant to Oncology, with search terms developed by studying the relevant literature. Literature to be included in the review was selected based on a set of pre-determined inclusion and exclusion criteria. Data relevant to the review aims was extracted from the literature and presented using a narrative synthesis approach.

Message for the Clinic

Previous reviews have established that failing to have discussions about diagnosis and prognosis is associated with poor patient outcomes. This review indicates that clinicians do not always disclose diagnostic and prognostic information to their patients, and consider a number of factors when making this decision. Non-disclosure conflicts with patient preferences and National Health Service guidelines, and without this information, people cannot be autonomous and make informed decisions about their care.

Introduction

Historically, doctor-patient relationships were predominantly paternalistic.^[1, 2] Clinicians were seen as the sole decision makers who acted on their own judgement based on what they believed to be in a patients' best interest.^[3] It was common practice to withhold a cancer diagnosis from patients (69-90% of clinicians).^[4, 5] However, there has been a significant shift in care towards patient autonomy and shared decision-making, whereby patients have the right to make fully informed decisions on their own behalf,^[6] and thus have the right to be fully

informed about their diagnosis in a timely manner.^[7] Cancer is no longer always viewed as a death sentence as it once was.^[8] Survival rates have improved as a result of increasing public awareness, early diagnosis and improved treatments.

Literature reviews examining patients' preference for diagnostic information in cancer conclude that the majority of patients wish to know their diagnosis and receive all the information related to this, both good and bad.^[9] In this review, 'prognosis' communication is defined as discussing approximate survival period with patients, providing a medical estimate of time until death, and/or informing patients that their illness is terminal and they will die from their illness. Reviews regarding prognosis have concluded that the majority of patients with both early and advanced cancer want this information, and for this to be delivered in an open and timely manner to allow them to make realistic plans and feel more control over their illness.^[10, 11]

Open discussions about prognosis are perhaps even more important in the context of a serious illness. A relatively recent review of the literature concluded that there are substantial and consistent associations between failing to have or delaying these discussions and poor patient outcomes.^[12] Furthermore, there is evidence from multiple research studies that discussions around prognosis and end-of-life do not harm oncology patients psychologically.^[12] Such open discussions can increase patients' prognostic awareness thus helping to reduce aggressive medical care near death ^[13, 14] and increase hospice care.^[14, 15] These factors have been associated with better patient quality-of-life (QoL) near death ^[13, 14, 16], which in turn has been related to bereaved caregivers feeling less regretful and more prepared for the patient's death, their self-reported health, mental health, and physical functioning, and a reduced risk of developing major

depression.^[14] Grieving caregivers of patients who received aggressive treatments had worse QoL, self-reported health, and increased role limitations compared to caregivers of patients who did not receive aggressive treatments.^[14]

It is important to consider how patients' make sense of and adjust to a serious medical condition, and how this then effects patient outcomes. One theory which can be used to discuss this is that of illness perceptions^[17]. This theory suggests patients develop a set of interrelated beliefs to make sense of their illness, which then provides a basis for their coping responses. This model aims to explain adjustment both at the point of diagnosis and throughout the illness, and states patients use knowledge, experience, and information received from health professionals to construct their illness perceptions^[18]. The effect of the information received from professionals regarding illnesses in developing patient's illness perceptions has been studied. It has been found that cancer patients who perceived they received more disease-specific information had stronger perceptions of personal and treatment control, and a better understanding of their illness^[19]. Moreover, in a study concerning brain tumour patients it was concluded that those who perceived the information given, sought, and verified by professionals during diagnostic communication to be good, then had a better understanding of their illness, and consequently a higher QoL^[20].

The relationship between illness perceptions and health-related outcomes has been widely studied^[21]; and they have been found to have an influence on patient anxiety and depression^[22, 23], satisfaction with medical consultations, future healthcare use, subsequent self-management, and quality of life^[24].

In order for illness perceptions to develop, and for these to be able to provide an appropriate basis for patient's adjustment and coping responses, it is necessary for patients to have access to information regarding their condition, such as their diagnosis and prognosis.

Accordingly, communicating diagnosis and prognosis is now seen as an essential skill of clinicians who have this responsibility in their occupation.^[25] Communication guides are available for clinicians on how to deliver news regarding cancer that could seriously affect patients views of their future,^[26] as well as how to disclose prognosis, develop patients' prognostic awareness, and discuss their care goals.^[12, 27] These guidelines are based on the assumption that patients have already been made aware of their diagnosis, and state that clinicians have a responsibility to provide patients with prognostic information, and advise that clinicians should be honest and direct with this, while acknowledging the inevitable uncertainty of the situation as well as the patients' emotional reactions.^[12]

Examinations of clinicians' personal opinions about diagnostic disclosure have revealed that 81-96.5% stated they believe patients should be told their diagnosis.^[28-32] However, peoples' personal beliefs and their actions may not always match, and it is possible that clinicians' opinions about disclosure do not correspond with their clinical practice.

This review aims to synthesise the literature in relation to clinicians' general practice regarding disclosure of diagnosis and prognosis in cancer (i.e. their general disclosure practice; GDP), and the clinician and patient factors associated with these practices.

Research questions:

- What are clinicians' general disclosure practices of diagnosis and prognosis in cancer?
- What are the patient and clinician factors associated with disclosure practices?

Methods

Search Strategy and Selection Criteria

A search of seven databases that are relevant to Oncology; MEDLINE, PsycInfo, CINAHL Complete, Academic Search Premier, PsycArticles, Web of Science, and SCOPUS, was conducted up to and including May 2016. The following search terms were used:

Abstract (AB) (Preference* OR Perspective* OR Thought* OR Opinion* OR Attitude* OR Manner* OR Style* OR Practice* OR Approach* OR Method* OR Technique*)

AND Title (TI) (Clinician* OR Physician* OR Professional* OR Specialist* OR Practitioner* OR Oncolog*) AND TI (Diagnos* OR Prognos* OR "Truth telling" OR "Truth disclosure" OR "Bad news" OR "Unfavourable news" OR "Unfavourable information")

AND (Communication OR Disclosure OR Feedback OR "Deliver* news")

AND AB (Cancer OR Oncology).

The search terms were developed by studying the relevant literature for appropriate terms. The following inclusion criteria were applied: data was from clinicians' perspective concerning their diagnosis and/or prognosis GDP directly

with adult oncology patients; articles had quantitative methodology; papers were original research articles in full text, published in English in peer-reviewed journals.

Studies were excluded from the analysis if: profession was unclear or did not involve adult oncology; participants were unqualified; data was from the perspective of anyone other than the clinician (e.g. patient, family); data regarded specific previous patients or hypothetical patient vignettes; data did not regard GDP (e.g. opinions of what should be disclosed); diagnosis was unclear or not cancer. Studies were also excluded if they employed qualitative designs; were review articles; or were pre-1995. This final exclusion criteria was applied as it was believed that research conducted before this time would not contribute to current knowledge of clinicians' GDPs.

Database searches and initial screening of titles and abstracts were conducted by the chief reviewer (FSE) according to the pre-determined selection criteria. If it was unclear from assessment of the title and abstract whether selection criteria were met, the full text was evaluated. Any further ambiguity led to full text assessment by the two other authors for determination of inclusion. Figure 1 illustrates the search procedure.

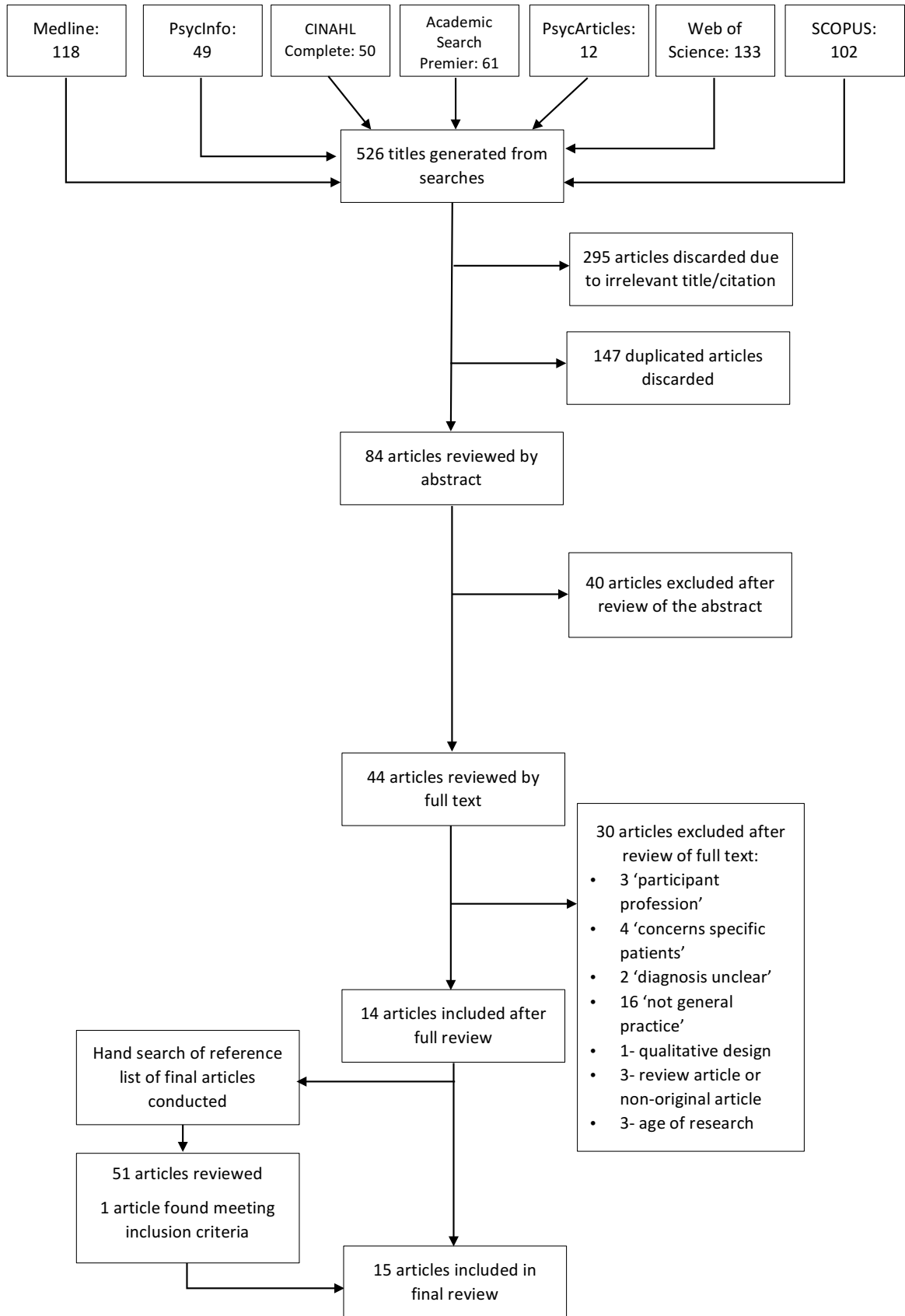


Figure 1. Flow diagram showing literature selection procedure.

Quality Assessment

Quality assessment was conducted on all articles with a checklist adapted from STrengthening the Reporting of OBservational studies in Epidemiology (STROBE),^[33] Downs and Black,^[34] and the Mixed Methods Appraisal Tool (MMAT)^[35] (Appendix D). A selection of articles were peer-rated to assess the reliability of quality assessment.

Results

Identification of Studies

The initial search yielded 526 articles. After excluding articles based on the above criteria (512) and adding one article retrieved from manual searches, 15 articles were identified that met selection criteria (Table 2, Figure 1)^[36-49]. Of the selected articles, six were conducted in western countries,^[38-42, 44] six in Middle Eastern countries,^[37, 43, 45, 48-50] two in Asia,^[36, 47] and one in Africa.^[46] Two of the studies concerned a specific type of cancer,^[36, 47] while the remaining studies did not.^[37, 39-41, 44-46, 48, 49] Sample sizes in the papers ranged from 45 to 729. In total, the studies contained 3479 participants from a range of professions including Oncologists, Haematologists, Radiologists, Primary Health Care Physicians, General Practitioners, Specialists in Palliative Care, Internal Medicine, Surgery, Obstetrics and Gynaecology. Most papers ($n=11$) included a range of specialties in their sample, with only four looking at specific clinician groups.^[43-45, 47] Some participants had undeclared speciality or no specialist qualification, and only one article included Nurses.^[45] All studies were cross-sectional designs using questionnaires to gather results.

Quality Assessment

The articles were of a range of quality levels, from 30.7-90%. Inter-rater reliability for quality assessment was high, with assessors agreeing on 92% of the criteria. Any disagreements were discussed between the assessors until a consensus was agreed.

Overall, the articles scored highly for their explanation of the relevant background literature and rationale for the investigation, describing participants' demographic details, providing a clear account of the main findings, and giving a cautious overall interpretation of their results. However, articles lost marks for not stating what type of cancer the participants specialised in, not having a representative sample, and not explaining how the sample size was derived.

Throughout this article, the term 'disclosers' will be used to describe clinicians who always or usually disclose diagnosis or prognosis, and the term 'non-disclosers' will be used for those who usually do not or never disclose diagnosis or prognosis.

Diagnosis

General Disclosure Practice

Thirteen articles^[36-43, 45-49, 50] examined clinicians' GDP for cancer diagnosis. Table 1 illustrates the GDPs of diagnosis reported between 1996 and 2015 in five-year periods. Studies illustrated that clinicians would also disclose the diagnosis 'just in some cases' or sometimes (52.2-78%),^[39, 42] 'just in part' (18%),^[39] or at the patients request (40%).^[38] One study^[45] included Nurses in

their sample who reported lower disclosure rates than the clinicians in the study (2% always disclose, 62% rarely disclose).

Components of Practice

Clinician Factors

Demographics

There are discrepancies in the literature regarding whether age of the clinician is associated with their GDP. One study illustrated older clinicians disclose more frequently ($p < .01$),^[45] while other research found older clinicians disclose less frequently ($p < .02$).^[36, 46] Additionally, one study found disclosers were significantly younger than non-disclosers ($p < .001$).^[49] Other literature found no statistically significant association between clinician age and GDP.^[37, 40, 43, 48-50] There is a general consensus in the literature that clinician gender,^[37, 40, 43, 46, 47, 48, 50] ethnicity,^[48] and religion^[36, 48] are not significantly associated with diagnosis disclosure.

Clinical

Speciality

Findings concerning the association between speciality and GDPs are mixed. There is a body of research that suggests no significant association.^[40, 41, 48-50] Other research has found surgeons ($p < .05$),^[39, 43, 46] oncologists ($p < .05$),^[43, 45] and medical specialists ($p < .05$)^[37] were more likely to disclose than other specialities in their sample. While other research states GPs, Primary Health Care practitioners ($p < .05$),^[37, 39] radiation oncologists ($p = .021$),^[43] internal medicine

($p=.000$),^[46] surgeons, and radiotherapists ($p=.001$)^[45] were less likely to generally disclose diagnosis than other specialities in their sample.

Clinical Experience

The majority of studies examining clinical experience found that this was not associated with GDP,^[43, 46, 47, 50, 48] while two studies state more experienced clinicians disclose the diagnosis more frequently ($p<.05$).^[37, 45]

Work Setting

Clinicians working in metropolitan areas or at facilities which performed more surgery per year disclose the diagnosis more frequently than clinicians working in non-metropolitan areas or at facilities performing less surgeries per year ($p<.01$), as found by one study.^[47] There is a disagreement as to whether the type of facility is associated with GDP. One study reported that clinicians working in 'other hospital' settings, as opposed to a university hospital or cancer centre, disclosed the diagnosis more frequently ($p=.008$).^[47] However, other research found no association between facility type and GDP.^[43, 50] Clinicians whose patients had access to support systems, such as psychiatrists and clinical psychologists, were significantly more likely to disclose diagnosis than those whose patients did not have access to such support ($p<.05$).^[47]

Training

GDP was not significantly associated with the country where the clinicians medical degree was obtained or with any post-graduate training outside of the

study country.^[37, 49, 48] It was indicated by one study that clinicians with little or no training in communicating diagnosis or prognosis, disclose significantly less than those with training ($p=.013$).^[43]

Personal Factors and Beliefs

A large proportion of clinicians in one study (81%) stated that personal attitudes about cancer are important when developing their disclosure policy. Over half (55%) believed these were less important than other factors, 23% reported they were more important, and 22% said they were of equal importance.^[36] Clinicians personal discomfort and difficulties with disclosing diagnosis was cited as a factor when deciding whether to disclose by 35% of clinicians in one study, but only 13% indicated it to be especially important.^[36] Contrasting findings from another study suggested clinicians' personal discomfort, or not being prepared to manage the situation, is not a reason for non-disclosure.^[38] This study also reported the most frequent reason for non-disclosure was the belief this is psychologically harmful for patients (85%), and to a lesser extent that the diagnosis was not useful to the patient (23%).^[38] While not significant, one study suggested there may be an association with clinicians having family experience of cancer and a lower tendency to disclose the diagnosis to patients ($p=.06$).^[50] There was no significant difference between disclosers and non-disclosers regarding the belief that information about cancer can improve patients' ability to cope reported by one study (72.2 vs 66.2% respectively).^[50]

The belief that patients want to know the diagnosis and have the right to know has been found to be significantly higher among disclosers ($p<.01$),^[49, 50] while the belief that patients do not want to know is cited as a reason for

concealing the diagnosis in one low quality study.^[41] On the other hand, GDPs were not influenced by the belief that disclosure may positively affect patients' coping capacity or their compliance with treatment.^[50] but were influenced by a concern about the psychological impact of disclosure.^[41] Clinicians 'ethical principles' were considered as a factor determining GDP by 17% in one study, but as there is no definition provided for this term it is difficult to interpret meaning.^[40]

If the Clinician had Cancer

Six articles^[36, 37, 40, 44, 46, 48] examined what clinicians' personal disclosure preferences would be if they had cancer. The majority of clinicians across studies said they would want to be told their diagnosis (63.6-89%),^[36, 37, 40, 46, 48] with smaller amounts saying they would not (9.2-22%),^[40, 46, 48] or they did not know (6-21%).^[40, 46]

Comparisons of clinicians' GDP and their personal wish to be told if they had cancer reveals significant differences. Elwyn et al. (1998) reported those who tend to disclose the diagnosis to patients wished to be told themselves more often than those who do not disclose ($p < .01$).^[36] Conversely, Hamadeh and Adib (1998) found the opposite effect with those who do not usually disclose the diagnosis to patients being significantly more likely to state they would wish to know their own diagnosis (99% vs 78%, $p < .05$).^[37] While Ozdogan et al., (2006) found no significant effect.^[43] When comparing the quality of these studies, the latter two scored 77% while Elwyn et al. (1998) scored 86%. Interestingly, more clinicians reported they would wish to be told the diagnosis than the number who reported they usually disclosed this to their patients.^[36, 37, 40, 44, 46]

Patient Factors

This review found a number of patient factors that clinicians consider when making a decision whether to disclose diagnosis or not. This was examined in a number of studies ($n=8$) as simply the percent of clinicians who stated they considered the factors.

Demographic and social factors clinicians consider are patients age (41-100%),^[36, 37, 39, 40, 47, 48] gender (4-71%),^[36, 37, 40, 47, 48] cultural background (20%),^[40] religion (12.8-25%),^[47, 48] community standing (30.5-58%),^[36, 37, 47, 48] family situation (21%),^[40] 'state of affairs' (68%),^[37] and if the patient is a clinician or nurse (44.8-87%).^[36, 40, 48]

Medical factors included patients' medical knowledge (52-65%),^[37, 48] the condition of the patient, including consciousness (80.1%),^[47] prognosis (15-76%),^[36, 37, 40, 45, 48] and compliance with treatment (51-82%).^[37, 47, 48] Other factors clinicians considered were the patients personality (74%),^[40] perceived emotional stability (74-92%),^[37, 48] anticipated emotional reaction (54%),^[40] their desire to know the diagnosis (14.5-85%),^[37, 47, 48, 49] and perceived intelligence or educational level (14-67.7%);^[36, 37, 40, 47, 48] with one study reporting over half of clinicians were more likely to disclose to patients considered to be of high intelligence (55%) and less likely to disclose to patients of low intelligence (57%).^[36] It is of note that Mystakidou et al. (1996) and Oliveira et al. (2015) are two of the lowest quality studies in the review (50% and 31% respectively), which should be taken into account when considering findings.

Some research furthered this and investigated the statistical significance of the patient factors. This showed that community standing ($p<.05$),^[49] state of

affairs ($p < .001$),^[49] patient as a clinician ($p < .05$),^[49] histological grade of illness ($p = .005$),^[47] and compliance with treatment ($p < .05$)^[37] were found to have significant associations with GDP. However, cultural background,^[37] mood,^[43, 45] emotional stability,^[49] educational level,^[43, 49] medical knowledge,^[43, 49] and prognosis,^[43, 45, 49] were found to have no significant effect on disclosure. It is important to note that most of these factors were only investigated by single studies so this review is unable to report whether these findings are consistent across studies in these cases. Additionally, community standing and state of affairs are not defined within the research so this is difficult to interpret what it is about these aspects that clinicians are influenced by.

There are disparities in the literature regarding the significance of other factors, with research finding both significant and non-significant effects of gender ($p = .001$;^[43] NS^[49]), age ($p < .05$;^[37] NS^[43, 45, 49]), religion ($p = .017$;^[49] NS^[43]), and patients desire to know ($p = .003$;^[49] NS^[43]). Additionally, patients refusing to know the diagnosis did not have a significant effect on GDPs as examined by one study.^[49] Methodological quality and design did not appear to account for the significant variance in findings regarding age and its influence on practices.

When Relatives Request Concealment

A number of articles in this review examined what happens when relatives request the diagnosis to be concealed from the patient. Across these studies the majority of clinicians (73-92.3%) have experienced patients' relatives requesting the diagnosis be withheld, and reported that this can influence their practice.^[36, 37, 39-41, 43, 45-47, 50] One study reported clinicians disclosed to patients less often if they reported feeling influenced by relatives' requests to withhold this

information, compared to clinicians who do not feel influenced by this (42.3% vs 63.3% respectively, $p=.017$).^[43] In multiple studies, when relatives request concealment, 51.8- 79% of clinicians reported they would comply and not disclose to the patient,^[36, 47, 50] while only 5-9% would oppose this request and disclose.^[36, 47] In one study, 43.2% of clinicians would only disclose after they had persuaded the relatives.^[47] It is important to note there appears to be an outlier in the literature, with Nwankwo and Ezeome reporting a much lower compliance rate and much higher opposition rate to this request (22% and 79% respectively).^[46] This Nigerian study also found that 85% rarely or never disclose the diagnosis to relatives before the patient, while a smaller amount (15%) generally or always did.^[46]

Over half of clinicians in Blazekovic-Milakovic et al.'s (2006) study reported they believed the diagnosis could be disclosed to relatives without the patient's consent.^[42] When clinicians do not disclose to the patient, the majority in two studies (60-99%) stated they always or usually tell a relative.^[36, 44] When relatives oppose disclosure but patients want this, there is an equal split in one study between clinicians who were more or less likely to disclose in this situation (35% apiece), while some felt neutral regarding this (22%).^[36] Only one study reported no significant effect of relatives' wishes on disclosure practice,^[49] and the majority of clinicians (93.2%) in one study believed it is beneficial to involve relatives when disclosing the diagnosis.^[39]

Prognosis

General Disclosure Practice

Three articles^[44, 46, 47] examined clinicians' GDP regarding cancer prognosis. Across these studies, 0.6-46.8% of clinicians always 'tell the truth' about prognosis,^[46, 47] 6.9-31.2% generally do, 22.0-45.7% rarely do, and 0-46.8% never do, dependent on the stage of the cancer.^[46] One high quality (90%) study reported that 98% of oncologists state "I tell them they will die of their illness".^[44] Other literature states the majority of clinicians rarely or never give a survival estimate (57-98.8%), while a smaller amount always or usually do (0-43%).^[44, 46]

Components of Practice

Clinician Factors

This review found the percentage of clinicians who disclose prognosis does not differ significantly between clinician gender or years of practice.^[46, 47] Age was found to be associated with prognostic disclosure, with younger clinicians being significantly more likely to disclose prognosis ($p=.007$ ^[44] & $p=.003$ ^[46]), and older clinicians significantly less likely ($p=.004$).^[44] One study suggested Jewish clinicians were significantly less likely to disclose prognosis compared to those who were Christians, of 'other' religions, or where religion was not applicable ($p=.018$).^[44] Additionally, in one study medical speciality was found to have an effect on prognosis disclosure, with surgeons being significantly more likely to disclose prognosis than other specialities in their sample ($p=.000$).^[46] This study also found that receiving formal training on palliative care was associated with clinicians being significantly more likely to disclose prognosis ($p=.01$).^[46]

Regarding the facility clinicians work in, this review found inconsistent evidence for its effect on prognostic disclosure. For example, one study^[44] found those working in solo private practice were significantly less likely to disclose prognosis compared to those working in a private group, medical school, or 'other' environment ($p<.001$).^[44] Conversely, another study found clinicians' GDPs did not differ significantly with facility type.^[47]

Clinicians working at facilities that perform surgery on more than 50 patients per year more frequently disclosed prognosis to patients compared to clinicians working at facilities performing surgery less frequently ($p=.014$),^[47] as found by one study. There is disagreement in the literature concerning whether the number of cancer patients seen by clinicians is significantly associated with prognosis disclosure, with some research reporting it is ($p=.011$)^[44] and another reporting it is not.^[46]

Clinicians in metropolitan areas have been found by one study to disclose prognosis more frequently to patients compared to clinicians in nonmetropolitan areas ($p=.009$).^[47] Additionally, clinicians were more likely to disclose prognosis to older patients when patient support systems were available ($p<.05$).^[47]

If the Clinician had Cancer

One, high quality, study explored clinicians' own preferences regarding prognosis if they were to be diagnosed with cancer.^[44] In this study 74% of clinicians reported they would want to know this information, including a time frame as to when death is expected. Clinicians who would not want to know their own prognosis were less likely to tell their patients ($p=.004$), whereas those who would want to know were more likely to tell their patients ($p<.001$).^[44]

Patient Factors

Prognosis disclosure practices did not differ significantly according to the patients' age. However, the techniques used for explaining prognosis to patients of different ages do appear to differ, with clinicians more frequently using concrete figures to explain this with younger patients.^[47] Furthermore, GDP did not differ significantly according to the histological grade of cancer.^[47] However, when comparing between stages of cancer, clinicians more frequently disclose the truth about prognosis to early stage cancer patients in comparison to late stage.^[46] Only two studies examined patient factors, and there are noticeably fewer factors examined in comparison to diagnosis research.

Only one study looked into relatives' involvement with disclosure of prognosis. This found that younger clinicians and those seeing more patients were significantly more likely to disclose prognostic information to relatives when this is not disclosed to patients ($p < .01$).^[44]

Discussion

This review suggests that clinicians do not consistently disclose diagnosis and prognosis to cancer patients. This stands in conflict with a review of patient preferences regarding information, which expressed patients desire this information.^[9] This is also in disagreement with current National Health Service guidelines which state services should be aiming for 95% of patients to receive a definitive cancer diagnosis within 4 weeks.^[7] Without this information, people will not be able to be autonomous and make informed decisions about their care and future. Additionally, the positive influence of patients receiving good information

regarding their diagnosis on their developing illness perceptions^[19,20] will not be achievable if the disclosure of the diagnosis is not made, and they therefore have no access to this information. Given the evidence that non-disclosure has implications for patient QoL and carer bereavement,^[12] disclosure rates should be ever increasing and interventions designed for healthcare systems should encourage this.

The available literature suggests there is a difference between clinicians' opinion regarding disclosure and their clinical practice; with more clinicians believing the diagnosis and prognosis should be disclosed in comparison with reported GDP. Comparing literature regarding clinicians' opinions,^[28-32] and matching the research by similar years to findings in this review, it is evident that reported GDPs are consistently lower than the amount of clinicians who believed patients should be told. For example, Grassi et al.^[39] found that almost half (44.8%) of clinicians reported they believed the diagnosis should always be disclosed, but in their clinical practice only a quarter (25.4%) actually always disclosed this. Also of note is the discrepancy between the number of clinicians who stated they would want to be told their diagnosis and prognosis if they had cancer, and the number reporting disclosing this information to their patients. However, the reasons behind the discrepancy remain unclear. It may be due to fear of strong emotional reactions from patients or a fear of psychologically harming patients,^[30, 38, 40] which could make the communication difficult for clinicians to manage personally. Alternatively, it could be the result of a lack of skill or confidence in managing strong emotions from the patient, which are an understandable reaction to being told distressing information and may demonstrate that patients have understood this information, but are nonetheless distressing for clinicians.

A further finding highlighted in this review is the high level of individual variances in GDPs amongst clinicians. The studies reviewed highlight a vast array of patient factors clinicians consider when deciding whether to disclose diagnostic or prognostic information. However, as there is so much inconsistency within the literature in this review, GDPs cannot be attributed to any consistent clinician, personal, or patient factors alone. For example, the cited differences in GDPs between specialities may not be due to personal preferences, but rather differences in service delivery and clinician responsibility.

This review suggests some clinicians disclose the diagnosis to a relative but not the patient or disclose to a relative before telling the patient. International medical ethics state that clinicians should respect a patient's right to confidentiality.^[51] However, this review cannot determine the possible reasons for this practice. For example, it is possible that in these circumstances patients had given permission for information to be shared with relatives, or that the patient did not have capacity. Another hypothesis could be that this is due to variance in the cultures of the country in which the research was conducted. Perhaps clinicians in collectivist cultures are more likely to involve relatives, and individualistic cultures perhaps less likely.

The current findings illustrate there may have been an increasing trend over time towards clinicians disclosing the diagnosis to oncology patients as general practice. This would mirror the healthcare guidance^[7] and be an encouraging advance considering the prevailing approach of patient autonomy. However, it is beyond the scope of this review to be able to fully examine this possible trend, considering all the factors that would need to be accounted for if this claim was going to be reliably made.

Implications for Practice

This review has drawn attention to the fact that not all clinicians routinely disclose diagnosis and prognosis in oncology. This exposes a need for interventions aimed at increasing diagnostic and prognostic disclosure rates to bring these in line with practice guidelines and patients' wishes. To aid clinicians with this communication, it may be helpful to increase communication training; as preliminary research suggested this increases disclosure rates^[35]. Providing education regarding patients' information wishes and the positive outcomes associated with disclosure may also be beneficial, as these factors have been suggested to increase disclosure rates.^[49, 50] Additionally, as this review has indicated clinicians' consider patients' anticipated emotional reactions to disclosures, supporting clinicians' in managing the emotional side of difficult disclosures would be valuable. Not only would this potentially increase disclosure rates if clinicians felt better equipped to manage distressing emotions, but it may also support clinicians' wellbeing. Possible ways of achieving this may be through peer support and reflective practice within disclosing clinicians. With this, it would also be necessary to develop means of effectively facilitating these approaches in busy medical settings and amongst highly trained medical staff. In addition to professional support systems and traditional training methods, it may be beneficial to consider the incorporation of service user involvement as a means to raise awareness of patient preferences for, and experiences of, diagnostic and prognostic disclosure practices.

Further Research

This review only found one study which examined the effect of diagnostic and prognostic communication training on disclosure practices. This is an important area to consider further as it was indicated that clinicians who had received the training disclosed more frequently.^[43] Rates of specialist communication training generally appear to be low,^[43, 44, 46] but large proportions of clinicians have expressed a need for such training.^[41, 45, 47]

We can see that diagnostic disclosure rates seem to be higher than they once were. However, not all cancer experiences are alike and a significant limitation of the current literature is that most studies did not state what type of cancer the clinicians worked with. Therefore, future research needs to explore the potential effects on patients of how these diagnostic disclosures are conducted in specific cancer types.

Limitations

The use of questionnaires throughout the literature in this review to gather data may limit or bias the results. For example, there is a lack of opportunity to elaborate on responses, and it would have been easy for clinicians to be dishonest about their GDP if they felt they were not following best practice. However, it may have actually allowed clinicians to be more honest as their responses were anonymous, and they were not having to report this directly to a researcher, as they would have with an interview based methodology.

This review predominantly includes research conducted in Western and Middle Eastern countries. However, it was beyond the scope of this review to

analyse how practices appear to differ between countries, which may limit the conclusions that can be drawn from this review.

Conclusion

Not all clinicians involved in the care of oncology patients report routinely disclosing diagnostic and prognostic information. This is in conflict with research on patient preferences and national guidelines.^[7, 9] GDPs cannot be attributed to any consistent clinician, personal, or patient factors alone due to a high level of inconsistency in the literature. With the now prevailing approach of patient autonomy and evidence supporting that these disclosures do not harm patients, but rather have positive outcomes,^[12] disclosure rates should be ever increasing.

Table 1. General Diagnostic Disclosure Practices of Clinicians from 1996-2015.

Years	Always/Usually Disclose	Never/Usually Do Not Disclose
1996-1999 [36, 37, 40]	11-47%	11-60%
2000-2005 [38, 39, 50]	25-47.3%	1.5-32.7
2006-2010* [42-45]	52-76%	0.8-48%
2011-2015 [41, 46, 47, 48, 49]	78-92%	8-31%

*Note: Nurses were excluded from the 2006-2010 cohort as their disclosure rates were significantly lower. See text for details.

Table 2. Clinicians General Disclosure Practices of Diagnosis and Prognosis from 1996-2015.

Author	Year	Country	Sample			General Disclosure Practice	Quality Score	
			N	Profession/Specialist	Cancer Site			Setting
Mystakidou, Liossi, Vlachos, & Papadimitriou	1996	Greece	228	Oncologists Radiologists Palliative care specialists	NR	NR	<i>Diagnosis</i> Always disclose- 11% To some patients- 78% Never- 11%	50%
Hamadeh & Adib	1998	Lebanon	212	Primary health care physicians, Medical specialists, Surgery	NR	NR	<i>Diagnosis</i> Usually disclose- 47% Usually do not disclose- 53%	86%
Elwyn, Fetters, Gorenflo, & Tsuda	1998	Japan	77	Generalists- 13% Internists- 34% Surgeons- 44% Radiologists- 9%	Specific questions about cervical,	Private medical school hospital and	<i>Diagnosis</i> Usually disclose- 40% Usually do not disclose-60%	77%

breast,
 prostate,
 colon,
 stomach,
 pancreatic,
 and lung
 cancer

Hospitals-
 48.9%
 GPs- 31.1%
 Specialist
 health
 services-
 6.6%
 Other public
 or private
 health

Always disclose- 25.4%
 Just in some cases 52.2%
 Just in part 18%
 Never disclose- 1.5%
 Answer omitted- 0.4%

61%

Grassi et al. 2000 Italy 675 23.2% NR

Surgery- 54.1%
 Internal medicine
 (including oncology)-
 23.2%
 No specialist
 qualification- 22.7%
 GPs

							services- 13.3%		
Goncalves & Castro	2001	Portugal	45	Surgery- 22.49% Medical Oncology- 12.27% Radiotherapy- 5.11% Other- 6.13%	NR	Oncological Centre	<i>Diagnosis</i> Disclose- 31% Do not disclose- 7% Rarely disclose- 22% At patients request- 40% Answer omitted- 2%	44%	
Qasem, Ashour, Al-Abdulrazzaq, & Ismail	2002	Kuwait	217	Internal medicine (82) Surgery (48) Obstetrics & Gynecology (73) Oncology (13)	NR	Three Public Hospitals Four specialised units of tertiary care.	Usually disclose- 67.3% Usually do not disclose- 32.7%	61%	
Blazekovic- Milakovic, Matijasevic,	2006	Croatia	134	General Physicians	NR	NR	<i>Diagnosis</i> Always disclose- 27.6% Sometimes- 71.6%	56%	

Stojanovic- Spehar, & Supe								Do not disclose- 0.8%	
<hr/>									
								<i>Diagnosis</i>	
							University	Always disclose- 7%	
Ozdogan et al.	2006	Turkey	131	Oncologists		NR	hospitals and	Usually disclose- 45%	73%
							'not university	Rarely disclose- 39%,	
							hospitals'.	Never disclose- 9%,	
<hr/>									
								<i>Prognosis</i>	
								Always discuss- 42%	
Daugherty & Hlubocky	2008	USA	729	Medical Oncologists		NR	NR	Ask patients if they want to know, and discuss if they say yes- 33%	90%
								Discuss if patients ask- 16%	
								Do not discuss- 0.4%	
								Other- 9%	
								<i>Missing- n=7</i>	

							<i>Diagnosis</i>	
							<i>Clinicians</i>	
							Always disclose-20%	
							Usually disclose- 56%	
Arbabi et al.	2010	Iran	100	Physicians (50) and Nurses (50) all in oncology (?)	NR	Hospital	Never disclose-2%	63%
							<i>Nurses</i>	
							Always disclose-2%	
							Rarely disclose-62%	
<hr/>							University	<i>Diagnosis</i>
						Hospitals (<i>n</i> = 102 clinicians)	Glioblastoma Disclose- 44.3% for patients aged <60 41.4% for patients aged ≥70	83%
Yamamoto et al.	2011	Japan	141	Surgical Neuro- oncologists. 98.6% brain tumour sub- specialty		Glioblastoma and Anaplastic Astrocytoma Cancer Centres (<i>n</i> = 10 clinicians)	Anaplastic Astrocytoma Disclose-	

61.5% for patients <60 years

'Other' 51.9% for patients ≥70 years

hospitals ($n=$
27 clinicians). *Prognosis*

Glioblastoma

<60 years-

34.3% explained approximate
survival period or survival rate using
figures

19.6% explained how much time the
patient could have left to work or
perform activities of daily living
unassisted, using figures

45.5% did not explain using concrete
figures

≥70 years-

29.3%, 16.4%, and 54.3%,
respectively

Anaplastic Astrocytoma

<60 years-

40.4%, 26.7%, and

32.9% respectively

≥70 years-

33.8, 22.8, and 43.5%, respectively

Diagnosis

Always disclose-46.8%

Generally disclose- 31.2%

Rarely disclose- 22.0%

Never disclose- 0%

56%

Prognosis

Nwankwo & Ezeome	2011	South-eastern Nigeria	173	General Practice	NR	Teaching hospital
				Surgery		
				Gynecology		
				Internal medicine		

Early cancer

Always- 46.8%

Generally- 31.2%

Rarely- 22.0%

Never- 0%

Advanced cancer

Always- 0.6%

Generally- 6.9%

Rarely- 45.7%

Never- 46.8%

Survival estimate

Always- 0%

Generally- 0%

Rarely- 1.2%

Never- 98.8%

Del Pozo et al.	2012	Qatar	131	13.0% Oncologists/ Haematologists, 14.5% Internists, 16.8% General Practitioners, 11.5% Paediatricians, 13.7% Obstetrician/ Gynaecologists, 7.6% Surgeons, 15.3% Another Specialty, 7.6% Undeclared Specialty.	NR	7 Hospitals and 22 outpatient centres	<i>Diagnosis</i> Disclose- 88.5% Do not disclose- 9.9% Answer omitted- 1.5%	83%
Naji, Hamadeh, Hlais, & Adib	2015	Lebanon	500	59% Surgical Specialty 33% Medical Specialty 8% Primary Care Physicians	NR	NR	Usually disclose-69% Usually do not disclose- 31%	83%

Oliveria, Fernandes, Santos, Bastos, & Cabral	2015	Portugal	120	47% Medical speciality (NR) 28% General Practice 25% Surgery	NR	University		
						Hospital		
						Centre and its	<i>Diagnosis</i>	
						Primary	Disclose - 92%	31%
						Healthcare	Do not disclose- 8%	
Units								
						(breakdown		
						NR)		

Author Contributions

Francesca Smithson Evans contributed to the concept and design of the review; data collection; data synthesis; and drafting of the article.

Dr Emma Wolverson contributed to the concept and design of the review, in addition to the critical revision of the article.

Dr Catherine Derbyshire contributed to the concept and design of the review, in addition to the critical revision of the article.

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Part Two: Empirical Paper

This Paper is written in the format for submission to *Neuro-Oncology Practice*.

See Appendix E for submission guidelines.

Illness Perceptions and Quality of Life in People Living with a Brain Tumour: Does Diagnostic Communication Have an Influence?

Running Title: The Role of Illness Perceptions of Brain Tumours in Quality of Life

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Abstract

Background: Research consistently demonstrates people with a brain tumor have low quality of life (QoL). Neuropsychological and tumor factors alone do not account for QoL, and research into illness perceptions remains neglected. Illness perceptions can be developed from information received from professionals. Medical communication is complex, and research has indicated patients' experiences of this can impact on a number of outcomes. This research investigated the possible mediation effects of illness perceptions on the relationship between diagnostic communication and QoL.

Methods: Participants with a primary brain tumor were recruited internationally. Quantitative measures included the Medical Communication Competence Scale, the Brief Illness Perception Questionnaire, and the Functional Assessment of Cancer Treatment-Brain. An optional qualitative response box allowed participants to express any further experiences. Mediation analysis was conducted to determine the mediation effects of illness perceptions on the relationship between diagnostic communication and QoL.

Results: The illness perception domain of Illness Comprehensibility had a mediating effect on the relationship between information communication and components of QoL. There was no evidence of Socioemotional Communication effecting QoL. Qualitative data suggests participants get their emotional needs met by their loved ones, rather than from professionals at diagnosis.

Conclusions: It is apparent that honest, clear, and timely information is important and beneficial to this population. Participants who rated the information components of communication higher had a better understanding of their brain tumor, which consequently improved their QoL. No effects of socioemotional communication being found does not detract from the importance of this conveyed in the qualitative data.

Keywords: Illness perceptions, communication, quality of life, brain tumors.

Background

A large scale UK study found that almost all of the 1017 respondents (91%) reported that their brain tumor had affected their emotional or mental health, and a third stated they had experienced depression, heightened emotions, chronic feelings of anger, disinhibition and changes in personality. Half of respondents said they live in constant pain, and two thirds stated they experience fatigue, with almost half (40%) being severely affected by this. Having a brain tumor can have a negative impact on peoples' relationships with those they are close to, and make people more reliant on others, which can be a source of distress for them.¹ Therefore, it is unsurprising that living with a brain tumor can impact quality of life (QoL), having to cope not only with the diagnosis of an incurable disease, but also the cognitive, behavioral, physical symptoms, and social consequences that come with this.^{2,3}

Quality of Life

QoL is a complex and elusive concept with no clear or universally agreed definition or standard for its measurement.⁴ For the purpose of this research, QoL will be described using the dimensions of physical wellbeing (PWB), social and family wellbeing (SWB), emotional wellbeing (EWB), functional wellbeing (FWB), and brain tumor-specific concerns.⁵ Despite difficulties in defining QoL this does not detract from its importance to people who are living with an illness that has a poor prognosis and high symptom burden, such as a brain tumor.

Research has consistently demonstrated that people living with a brain tumor experience significant symptom burden and low QoL.⁶⁻⁸ Fatigue,^{7,9} seizure frequency, motor impairments, decreased functional status,⁷ and depressive symptoms^{7,9} diminish QoL. There is a disagreement in the literature regarding whether tumor neuropathology has an impact on QoL. Taphoorn et al., 2010 suggested tumor size and location were associated with QoL,⁷ while Ownsworth et al. (2009) reported these factors, along with neuropsychological impairment, could not adequately account for QoL outcomes.¹⁰ Higher QoL has been associated with greater global cognitive ability, lower subjective impairment, higher overall satisfaction with support,⁸ and longer survival times.⁷ Neuropsychological and tumor factors alone do not account for QoL, therefore person-related factors must be considered. Coping² and adjustment¹¹ have been researched previously, but additional research is needed to investigate other possible concepts affecting QoL.

Illness Perceptions

People with the same illness will react to it in different ways, and as suggested above neuropsychological and tumor factors alone do not account for QoL; therefore, how people evaluate their illness may be more important than the illness itself. Illness perceptions can be described as a set of interrelated beliefs people develop in order to make sense of their illness, which then guide how they manage the illness.¹² Illness perceptions are constructed from previous personal or family experiences patients may have with their condition, the media and information received from health professionals.¹³

To date, there has been only one published study exploring illness perceptions in people living with a brain tumor.² Participants perceived their tumor to be chronic in nature, with strong negative consequences, and having a strong emotional impact on their life. It was suggested that participants perceived themselves as having some understanding of their brain tumor, and had a stronger belief in treatment control while they perceived personal control to be weaker. It is important to note that this research only included low-grade tumors, which may account for perceived treatment control being higher than personal control. Additionally, it found that illness perceptions explained a significant amount of variance in anxiety and depression, but not positive affect.² As it has been suggested that illness perceptions can be formed from information from health professionals,¹³ this is an important avenue to investigate.

Communication

The communication of a diagnosis, particularly a life-threatening diagnosis, is a critical event and can mark the beginning of an individual's journey with a serious illness. A patient's experience of this communication can influence their emotional wellbeing over the course of their illness.¹⁴ Oncology patient ratings of physicians' communication skills has been shown to significantly predict general and illness-specific wellbeing.¹⁵ Effective communication has also been related to improved understanding, medical adherence, and satisfaction.¹⁶ Conversely, when this communication is perceived to be poor, it can create denial, uncertainty, non-compliance, anxiety, depression, and problematic psychological adjustment.¹⁷

Medical communication is a complex process that can be separated into two central aspects of the interaction; information (giving, seeking, and verifying), and socioemotional or relational aspects.¹⁸ Regarding the communication of information, it has been reported that professionals can underestimate what patients want and need to know concerning their diagnosis.^{19,20} Diagnostic disclosure rates can be low²¹ and it is indicated Oncologists can purposely withhold information, assuming total disclosure will harm patients.²² Conversely, from the patients' perspective up to 95% wish to receive all the information available, both good and bad;²³ and people with brain tumors value detailed information at the point of diagnosis, to aid them in managing their now uncertain future.^{24,25} Access to information can influence adjustment to a brain tumor.²⁴ Uncertainty and a lack of information obstructs

patients understanding of their illness, impairs patients' sense of manageability, and increases the feeling of chaos and anxiety.²⁵

Socioemotional communication assesses relational aspects of diagnostic communication, such as warmth, trust, and the expression of care.¹⁸ Professionals' use of basic psychotherapeutic techniques, and their interpersonal manner during diagnostic communication has a significant positive influence on patients' wellbeing and coping.^{14,26} A positive relationship has been identified between compassionate physician behavior and reduced patient anxiety in cancer.²⁷ Furthermore, patients who believed their professionals affective tone was angry or irritated reported greater physical and psychological distress, and those who rated their physician as having an anxious or nervous tone reported lower global QoL.¹⁷ However, this research did not establish a relationship between information or socioemotional communication during initial oncology consultations and patient QoL.¹⁷ Fujimori and Uchitomi (2009)²³ identified multiple articles in a literature review which acknowledged emotional aspects, including offering comfort and support to patients, as being important parts of diagnostic communication as perceived by cancer patients. Some research suggests professionals believe the manner in which they disclose bad news, such as a life-threatening diagnosis, has little impact on patients.^{28,29} However, that is not a view held by all professionals.³⁰

There is guidance available for professionals for communicating with people living with brain tumors.³¹ This acknowledges the importance of professionals using easily understandable language during the diagnosis, and taking the time to provide

information and form a trusting relationship with people and their family.^{31,32}

However, there is a lack of research concerning how well implemented or successful this type of guidance is. Given the implications of communication on QoL, it is important to investigate how the communication of a diagnosis of a brain tumor is perceived and what influence this may have on QoL.

Aims

The main purpose of this study was to investigate any possible mediation effects of illness perceptions on the relationship between diagnostic communication and QoL. Through this, it was also aimed to determine whether in people living with a brain tumor: (1) diagnostic communication predicts illness perceptions; (2) illness perceptions predict QoL; and (3) diagnostic communication directly affects QoL.

Hypotheses

It was hypothesised that illness perceptions would have a mediation effect on the relationship between diagnostic communication and QoL in people living with a brain tumor. Additionally, it was hypothesised that diagnostic communication would predict illness perceptions and illness perceptions would predict QoL. It was hypothesised that diagnostic communication would not have a direct effect on QoL.

Materials and Methods

Design

This cross-sectional study employed a quantitative approach that incorporated an open-response question; quotes from which were subsequently used to aid in the interpretation and integration of the findings. The open-response question sought to gather additional information or reflections participants had on the concepts being measured; and was incorporated to allow participants the opportunity to convey opinions or experiences which could not be gathered from the quantitative measures.

Participants and Procedure

To be eligible for the study, participants had to be diagnosed with a primary brain tumor, low-grade or high-grade, 18 years old or above, and able to read English. Participants were excluded if they were under 18, could not read English, or had a secondary brain tumor. Participants were recruited internationally online via advertisement by brain tumor charities and organizations, and through active promotion of the research via social media by the chief investigator with the support of Brain Tumor/Psychology online communities. A sample size calculation determined a minimum sample of 118 participants was required to detect a mediation effect.³³

Measures

The patient version of the Medical Communication Competence Scale (MCCS)¹⁸ was used to investigate participants' experience of diagnostic communication. This measures participants' perceptions of the professionals competence in four domains; information giving (9 items), information seeking (4 items), information verifying (4 items), and socioemotional communication (7 items, maximum score 49). Responses are measured on a 7-point Likert scale. The information domains were combined into one variable, 'information combined', with a maximum possible score of 119. Reasonable support for the validity of the MCCS has been found.^{18,34}

One item of the MCCS under the heading 'The doctor explained the following to my satisfaction...' was amended from 'What I could do to get better', to 'What my treatment options were' as it was thought to be more in line with the nature of brain tumors.

The Brief Illness Perception Questionnaire (B-IPQ)³⁵ was utilized to measure illness perceptions. This comprises of nine items forming four components: Cognitive Representations (five items: Consequences, Timeline, Personal Control, Treatment Control, and Identity), Emotional Representations (two items: Concerns and Emotions), Illness Comprehensibility (one item: Coherence), and Causal Representation (one item: causes). Responses are given on 10-point Likert scales where higher scores indicate stronger perceptions along that dimension, bar the Causal Representation item, which is assessed with an open-ended question. Questions regarding personal and treatment control, and coherence are reversed,

meaning that higher scores are seen as being beneficial. The B-IPQ has shown good test-retest reliability and good concurrent and discriminant validity.³⁵

The Functional Assessment of Cancer Treatment- Brain (FACT-Br)⁵ was used to measure QoL. The FACT-Br gathers information about Total QOL, which is general QoL combined with Brain Tumor specific concerns, as well as information about the dimensions of Physical Wellbeing (PWB), Social/Family Wellbeing (SWB), Emotional Wellbeing (EWB), and Functional Wellbeing (FWB). The FACT-Br has been validated and shown high validity and reliability.³⁶

An optional qualitative response box, where participants were able to report any additional reflections they had on the concepts being measured was included at the end of the questionnaire. This element was considered important given the novelty of the research, and allowed participants the opportunity to convey any opinions or experiences which could not be gathered from the quantitative measures (see appendix H).

Data Analysis

Statistical Analysis

Descriptive statistics were calculated for demographic and physical variables. Mediation analysis was conducted using PROCESS Macro version 2.15³⁷ to determine the mediation effects of illness perceptions on the relationship between diagnostic communication and QoL. Mediation is a hypothesized causal chain in which the independent variable affects a second variable (the mediator) that, in turn,

affects the outcome variable. Independent variables were the components of the MCCS; Information Combined and Socioemotional Communication. Outcome variables included five components of the FACT-Br; Total QoL, PWB, SWB, EWB, and FWB. Mediator variables were the illness perceptions domains, namely Cognitive Representation, Emotional Representations, and Illness Comprehensibility. Therefore, in total, ten mediation analyses were completed.

The Statistical Package for Social Sciences IOS version 23.0 was used for all statistical analyses.

Qualitative Analysis

Data from the illness perception domain of Causal Representation was manually sorted into categories (see appendix I), which are displayed as frequencies (table 2).

Thematic analysis was used to interpret the qualitative data from the open response box, using recommendations from Braun and Clarke (2006).³⁸ Following coding of the data by the chief researcher (FSE), a second researcher (EW) reviewed the data adding further codes. Next, the codes were formed into themes, and these were refined from re-examination of the data and in discussion with a second researcher (EW) (see appendix I).

Results

Participants

A total of 138 participants completed the questionnaire. A further four participants chose to withdraw during the questionnaire using the discontinue option, and 87 exited the questionnaire not using this option and without giving a reason. This is most likely due to the length of the questionnaire proving too tiring for some participants, or due to the emotive nature of the study.

Table 1. Participant Demographics ($n= 138$).

	Frequency % (n)
Total	100 (138)
Gender	
Male	26.1 (36)
Female	73.9 (102)
Age	Mean= 44 (SD= 10), Range: 22-73
Ethnic Group	
White/Caucasian	94.2 (130)
Mixed/Multiple Ethnic Groups	2.9 (4)
Asian/Pacific Islander	2.2 (3)
Other	0.7 (1)
Grade of Brain Tumor	

I	25.4 (35)
II	29.7 (41)
III	5.1 (7)
IV	12.3 (17)
Unsure	27.5 (38)
Country in which diagnosis was received	
UK	51.4 (71)
USA	16.7 (23)
Canada	15.9 (22)
Australia	8.7 (12)
New Zealand	3.6 (5)
Other	3.6 (5)
Received diagnosis from	
Neurosurgeon	43.5 (60)
Neurologist	21.7 (30)
GP	10.1 (14)
Oncologist	6.5 (9)
A&E Doctor	6.5 (9)
ENT Doctor	2.9 (4)
Unsure	2.2 (3)
Other	6.5 (9)
Other active medical condition(s)	

Yes	50 (69)
No	50 (69)

Diagnostic Communication

Participants' ratings of the Information Combined components of communication ranged from 17-119, with a mean of 75.88 ($SD= 29.15$). Higher scores indicate the perception of better communication. Regarding Socioemotional Communication, ratings ranged from 7-49, with a mean of 34.15 ($SD= 12.90$).

Illness Perceptions

The range of scores from the B-IPQ indicate participants have very variable perceptions of their brain tumor. Mean scores suggest participants perceived their brain tumor as causing them high Concern ($M=6.97$; $Range= 0-10$; $SD= 2.57$), negatively affecting their life (Consequence, $M=6.57$; $Range= 1-10$; $SD= 2.35$) and them emotionally (Emotional Representations, $M=6.64$; $Range= 0-10$; $SD= 2.58$), and participants were worried it will progress (Timeline, $M=6.71$; $Range= 0-10$; $SD= 2.66$), Overall participants in the sample perceived they had low Personal Control ($M=2.75$; $Range= 0-10$; $SD= 2.88$) over their brain tumor, but had a stronger belief in Treatment Control ($M=6.01$; $Range= 0-10$; $SD= 3.24$). Scores suggest that participants have formed an understanding of their brain tumor but this is not particularly strong (Coherence, $M=6.72$, $Range= 0-10$; $SD=2.87$). Regarding Identity (symptoms) participants did not appear to have a strong illness identify; with a mean

of 5.13 (*Range*= 0-10; *SD*= 2.90) for how symptomatic they perceive themselves to be.

Causal Representation

Participants reported a wide range of beliefs about what may have caused their brain tumor; categories of which are reported as frequencies in table 2.

Table 2. The most important Causal Representation as rated by participants. ($n=138$).

Causal Representation	Frequency % (n)
Physical- internal (<i>e.g. genetics, hormones</i>)	38.4 (53)
Uncertain	19.6 (27)
Stress	8.0 (11)
Environmental	7.2 (10)
Lifestyle	7.2 (10)
Bad luck	6.5 (9)
Other	6.5 (9)
Physical trauma (<i>e.g. head injury, fall, car crash</i>)	4.3 (6)
Demographics	2.2 (3)
<i>Total</i>	<i>100.0 (138)</i>

Quality of Life

Similarly to the variance of illness perceptions, it is apparent that participants also had very varied QoL. Participants QoL appeared consistent across the components, and there was no aspect of QoL that was significantly lower than the others (Table 3).

Table 3. Means, Ranges, and Standard Deviations for QoL components. 95% CI. (n=138).

QoL Component	Mean	Range	SD
Total QoL	108.3	42.00-175.00	27.80
PWB	17.40	0.00-28.00	6.48
SWB	18.19	0.00-28.00	6.42
EWB	12.17	2.00-22.00	4.84
FWB	14.68	3.00-28.00	6.33

Abbreviations: QoL: Quality of Life; PWB: Physical Wellbeing; SWB: Social/Family Wellbeing; EWB: Emotional Wellbeing; FWB: Functional Wellbeing.

The Mediation Effects Of Illness Perceptions On The Relationship Between Diagnostic Communication And Quality Of Life

In mediation models, a direct effect shows that two variables are related independent of the mechanism represented by the mediator variable, in this case, illness perceptions. An indirect effect shows that two variables are related through the mediator variable. If there is an indirect effect present, it can be said that M acts as a mediator of the effect of X on Y ($X \rightarrow M \rightarrow Y$)³⁷.

Information Combined

Illness Comprehensibility had a mediating effect on the relationship between Information Combined and Total QoL, SWB, and FWB. Information Combined indirectly influenced Total QoL through its effect on Illness Comprehensibility. Participants who perceived the information aspects of diagnostic communication to be better ($a=.022$, $p=.006$), had stronger perception of Illness Comprehensibility, which then led to higher Total QoL ($b=1.455$, $p=.041$). A bias-corrected bootstrap confidence interval for the indirect effect ($ab=.033$) based on 1000 bootstrap samples was entirely above zero (.003 to .084). There was no evidence that Information Combined influenced Total QoL independent of its effect on Illness Comprehensibility ($c'=.123$, $p=.073$).

Information Combined indirectly influenced SWB through its effect on Illness Comprehensibility. Participants who perceived the information aspects of diagnostic communication to be better ($a=.022$, $p=.006$), had stronger perception of Illness Comprehensibility, which then led to higher SWB ($b=.401$, $p=.038$). A bias-corrected bootstrap confidence interval for the indirect effect ($ab=.0091$) based on 1000 bootstrap samples was entirely above zero (.001 to .030). There was evidence that Information Combined influenced SWB independent of its effect on Illness Comprehensibility ($c'=.045$, $p=.016$).

Information Combined indirectly influenced FWB through its effect on Illness Comprehensibility. Participants who perceived the information aspects of diagnostic communication to be better ($a=.022$, $p=.006$), had stronger perception of Illness Comprehensibility, which then led to higher FWB ($b=.462$, $p=.006$). A bias-corrected

bootstrap confidence interval for the indirect effect ($ab=.010$) based on 1000 bootstrap samples was entirely above zero (.002 to .024). There was no evidence that Information Combined influenced FWB independent of its effect on Illness Comprehensibility ($c' = .028, p=.084$).

There was no evidence of an indirect effect of Information Combined on PWB or EWB mediated through illness perceptions. There was no evidence that Cognitive or Emotional Representations had an indirect effect on the relationship between Information Combined and any QoL components.

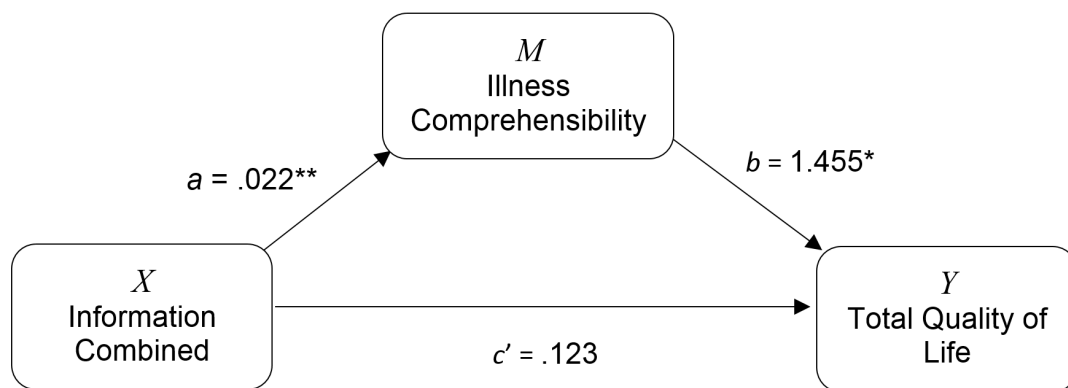


Figure 1. The indirect effect of Information Combined on Total Quality of Life mediated by Illness Comprehensibility.

* $p < .05$

** $p \leq .01$

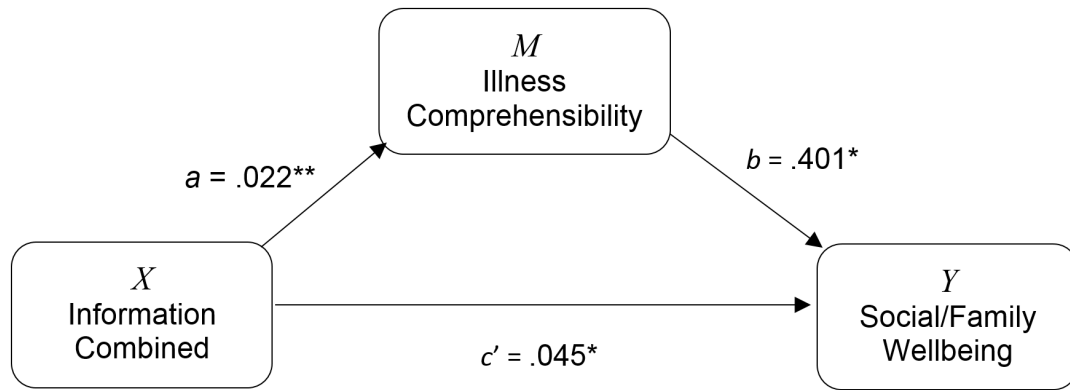


Figure 2. The indirect effect of Information Combined on Social/Family Wellbeing mediated by Illness Comprehensibility.

* $p < .05$

** $p \leq .01$

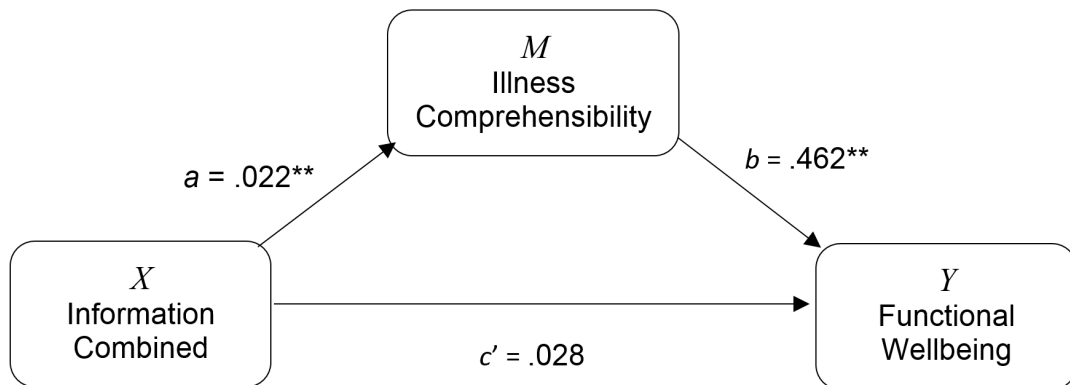


Figure 3. The indirect effect of Information Combined on Functional Wellbeing mediated by Illness Comprehensibility.

** $p \leq .01$

In the qualitative data, information participants received regarding their brain tumor diagnosis from professionals was predominantly expressed as being lacking, unclear, sometimes incorrect, or concealed for a period of time. It was also apparent that the information that was lacking was often fundamental information about participants' diagnosis and illness progression.

"i hear people talk about 1 2 3 4 i dont know what that means" (Participant 29).

"I was satisfied, to begin with but last year, as my condition worsened, I discovered that my tumor had been steadily growing for 3 years. However, after each six-monthly scan I was told that all was fine and there was no progression... I felt, and still feel, let down, disappointed and confused as to why I wasn't kept in the picture." (Participant 39).

Socioemotional Communication

There was no evidence of an indirect effect of Socioemotional Communication on any domains of QoL mediated through illness perceptions.

The Effect of Diagnostic Communication on Illness Perceptions

The Information Combined aspects of diagnostic communication significantly predicted the illness perception of Illness Comprehensibility ($\beta=.02$, $p=.006$), but not the domains of Cognitive or Emotional Representations. This indicated that how

participants' perceived the information given, sought, and verified during diagnostic communication, predicted how well they feel they understand their brain tumor.

The Socioemotional aspects of diagnostic communication did not significantly predict any domains of illness perceptions.

The Effect of Illness Perceptions on Quality of Life

Table 4 illustrates that Illness Perceptions accounted for between 11 and 56% of the variance in QoL. Additionally, domains of Illness Perceptions significantly predicted individual components of QoL. Participants Cognitive Representations of their brain tumour significantly predicted Total QoL, PWB, and FWB in a negative direction. Similarly, participants Emotional Representations of their brain tumor significantly predicted Total QoL, PWB, EWB, and FWB in a negative direction. This translates as the stronger participants' perceptions of Cognitive and Emotional Representations of their brain tumour were, the lower the above domains of their QoL were. Cognitive Representations did not predict SWB or EWB, and Emotional Representations did not predict SWB.

The illness perception of Illness Comprehensibility significantly predicted Total QoL, SWB, and FWB in a positive direction; meaning that the stronger participants' perceived they had an understanding of their brain tumor, the better these aspects of their QoL were. Illness Comprehensibility did not predict PWB or EWB.

Regarding the illness perception domain of Causal Representations (table 2), only hypothetical links can be made here. It is possible that those who were uncertain

about the cause of their brain tumor (19.6%) also perceived they had a weaker understanding of their brain tumor, and in turn a lower QoL. It may be that the small percentage of participants who believed aspects of their lifestyle caused their tumor (7.2%) may feel more responsibility or guilt surrounding their illness, which may in turn lower their QoL. Considering participants' qualitative responses, perceived causes of their brain tumor did not emerge as a theme. This may highlight that the causes are not viewed as an important aspect of their life with a brain tumour post-diagnosis.

Table 4. Multivariate linear regression analysis of the effect of Illness Perceptions on Quality of Life with coefficients (β) and standard errors (SE). 95% CI. ($n= 138$).

Illness Perception Components	QoL Components				
	Total	PWB	SWB	EWB	FWB
Cognitive Representations					
$\beta=$	-.98***	-.32***	.03	.05	-.23***
SE=	.29	.07	.07	.04	.06
Emotional Representations					
$\beta=$	-2.58***	-.25*	-.22	-.81***	-.48***
SE=	.49	.11	.12	.06	.10
Illness Comprehensibility					
$\beta=$	1.45*	.06	.40*	.13	.46**
SE=	.70	.18	.19	.10	.16
R^2	.36	.22	.11	.56	.31
F	18.80***	9.62***	4.31**	43.48***	15.32***

Abbreviations: QoL: Quality of Life; PWB: Physical Wellbeing; SWB: Social/Family Wellbeing; EWB: Emotional Wellbeing; FWB: Functional Wellbeing.

* $p < .05$

** $p \leq .01$

*** $p < .001$

Direct Effect of Diagnostic Communication on Quality of Life

There was evidence that Information Combined had a direct effect on SWB independent of its effect on Illness Comprehensibility ($c'=.045$, $p=.016$). However, there was no evidence that Information Combined had a direct effect on any other domains of QoL.

There was no evidence of any direct effects of Socioemotional Communication on any domains of QoL. However, this is not to say that socioemotional aspects of professionals' interaction with participants were not deemed important. Approaches towards participants and the disclosure of their diagnosis was written about throughout the qualitative data. Some participants described very positive experiences, such as kindness, compassion, and honesty.

“Without exception they have been kind, compassionate, clear, honest and I feel fortunate to be under their care” (Participant 49).

Negative experiences of professionals' approach also involved socioemotional behaviours, for example professionals being patronizing, dismissive, and insensitive.

“He makes me feel uncomfortable about questioning him and is patronising and dismissive.” (Participant 42).

“The neurologist yelled at me for crying because she said it was a false tumor. As I was laying on a table after a lumbar puncture, she came in & told me I had either MS or a brain tumor & left the room.” (Participant 47).

Discussion

This study aimed to explore the potential mediating effect of illness perceptions on the relationship between diagnostic communication and QoL. In relation to this, only the illness perception domain of Illness Comprehensibility was found to have a mediating effect on the relationship between diagnostic communication and QoL. This demonstrates an important link between the information given, sought, and verified by professionals during diagnostic communication and participants subsequent QoL. Participants who rated the information components of their diagnostic communication higher then had a better understanding of their brain tumor, which consequently improved their QoL. However, in the qualitative responses many participants reported that, in their experience, information regarding their brain tumor was lacking. Participants reported the information they had received was unclear in some circumstances. For example, participants recalled being told the name of their brain tumor, or the grade, without this being explained, and thus felt they were not actually told they had a brain tumor. A recent literature review (F. Smithson Evans, unpublished manuscript)³⁹ regarding professionals self-reported diagnostic disclosure practices, supports the notion that information is not always provided to patients, both in general cancer and brain tumors more specifically. If the information provided during diagnosis is perceived as unclear, this will not promote strong Illness Comprehensibility, and a poor understanding is likely to lead to reduced QoL. The potential barriers to information sharing faced by professionals needs to be better understood and addressed so patients receive the appropriate information regarding their brain tumor.

Where an indirect (mediating) relationship has been discovered where there was no direct relationship, it can be claimed that there is no evidence of an association between the independent variable and the outcome variable when the mechanism of the mediator is accounted for. However, it shows there is evidence that the mediator variable has a mediating effect on the relationship between the independent variable and the outcome variable. In practice, this would suggest that diagnostic communication does not affect QoL independent of the influence of illness perceptions on QoL; but that there is an indirect relationship between diagnostic communication and QoL which can be explained through the mechanism of illness perceptions.

The finding that the information components of communication had a direct effect on participants SWB, for example how well they felt supported by their family, and how well their family had accepted their brain tumor, may be explained by thinking about their family's illness perceptions. It could be hypothesized that by also receiving this information, family members may have been positively influenced in their acceptance and understanding of the participants' diagnosis. This may have enabled them to better support their loved one, which, in turn, may have improved participants' SWB. The importance of this support was clear in the qualitative responses.

Socioemotional Communication did not predict illness perceptions, nor did it directly affect QoL. It is possible that while the socioemotional side of diagnostic communication was remembered well by participants who either had a particularly positive or negative experience, this was not enough to influence their illness perceptions. However, this may also be the result of limitations of the study design,

specifically the measure selected to explore communication. The MCCS only measures positive aspects of communication (e.g. 'showing compassion') and does not directly measure negative components of communication. In the open response box participants expressed a number of powerful negative emotions, both towards how they were communicated with and the experience of being diagnosed with a brain tumor on the whole. Additionally, as the MCCS focuses on one interaction it does not fully capture participants' experiences when they had a prolonged journey to diagnosis, or experienced being in limbo before seeing a specialist for more detailed information. Evidence of this comes through in participants' qualitative responses, which tended to focus on the journey to diagnosis as opposed to this being just one interaction. Additionally, almost 30% of participants in this sample were told their diagnosis by a professional without a brain-tumor or cancer specialty. This would leave them in limbo, with almost no information regarding their brain tumor or what the implications may be, which is likely to amplify the trauma of diagnosis.

From the qualitative responses it seems likely that participants get their emotional and support needs met by their loved ones and those in a similar situation to themselves, rather than from professionals at diagnosis. Reliance on loved ones for support after the diagnosis of a brain tumor has been established as critical in previous research²⁴. However, this reliance also came at a cost to some participants in this study. Participants described their role within their family having changed, strains developed, and sometimes ultimately relationships breaking down. This finding is consistent with research on family members of people living with a brain

tumor, who also reported significant relationship changes, with some relationships strengthened, some maintained, and others strained.⁴⁰

A further aim of this study was to determine whether illness perceptions predict QoL in people living with a brain tumor; this was confirmed by the results. Findings indicate that the stronger participants' Cognitive and Emotional Representations of their illness were, the lower their QoL; while the stronger participants perceived their Illness Comprehensibility to be, the better their QoL. For example, participants who were more concerned about their brain tumor and felt this had a greater impact on them emotionally, had significantly lower QoL. The relationship between illness perceptions on QoL has been well documented in other conditions, including Multiple Sclerosis,⁴¹ Epilepsy,⁴² late-stage cancer,⁴³ and Traumatic Brain Injury,⁴⁴ with similar findings reported throughout. Illness perceptions remain under researched in the brain tumor population. Developing a better understanding of the illness perceptions of people living with a brain tumor is clinically important, as this may be able to suggest the use of psychological interventions to support patients and develop services, as has been proposed in existing literature.⁴¹⁻⁴³

Limitations

The high proportion of participants who responded to the open response box may indicate they felt the quantitative measures were not enough to capture their experience fully; a possible limitation of the study methodology. It is worth considering whether the construct validity of the quantitative measures used in this

study was reliable; whether they actually measured the underlying constructs they purport to measure. For example, qualitative data expressed the complexity in participants' journeys and the daily difficulties they experience. It is therefore a possibility that the concept of QoL in itself is perhaps too simple to reveal the full picture of what it is like to live with a brain tumor. Not only this, but it is important to remain mindful that what might be considered a high QoL for one individual, may constitute as poor QoL to another. Therefore, with regard to implications for future research, a beneficial project may be to develop a measure specifically for people living with a brain tumor. It would be vital for this to capture aspects of living which are deemed important to this population which current measures neglect; such as financial concerns, the impact on driving, and implications of these.

Differences between healthcare systems across the countries in which participants received their diagnosis in this study may have influenced how they received their diagnosis. For example, some participants will have had access to free healthcare, while others will not have. Participants wrote about the financial implications that paying for private medical care brought, and the pressure of this is likely to impact their QoL, but financial concerns are an oversight in the FACT-Br, and could bring into question its construct validity. Unfortunately, it was beyond the scope of this research to examine the effect of country of diagnosis in any depth.

The sample size of this research was more than required to detect a mediation effect.³³ However, females were overrepresented in this sample. Additionally, participants were younger on average than the general brain tumor

population⁴⁵ which is likely to be due to the online design and social media advertisement being more likely to reach this demographic.

Implications for Practice

It is apparent that honest, clear, and timely information is very important and beneficial to this population. Services need to work in ways which ensure patients understand their brain tumor; which may mean reiterating important information, providing both verbal and written information, and providing follow-up support. However, this is not to say that all individuals want the same amount of information, and it will be important for services to offer tailored information by discussing with individuals what they want to know about the implications of their brain tumor. For example, qualitative data from this study highlighted that some participants did not want prognostic information, while others wanted all additional information available. As this research has indicated that illness perceptions consistently predicted participants QoL, it would be helpful for healthcare services to consider how to support people to develop appropriate illness perceptions of their brain tumor, as these have an important influence on their QoL.

Social and emotional support has been highlighted as important both in this research and existing literature, but that this is often neglected from healthcare services, particularly after treatment has finished. The need for follow-up and on-going support has been identified from participants' qualitative responses, and this needs consideration from services involved in the care of people with brain tumors.

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Part Three: Appendices

Appendix A: Epistemological Statement

This statements seeks to reflect on, and make clear, the ontological and epistemological stance underpinning this thesis and the research methodology chosen.

Ontological assumptions regard what constitutes reality and what there is to know about the world, while epistemological assumptions regard how knowledge about the social world can be created, acquired, and communicated (Snape & Spencer, 2003; Scotland, 2012).

Research using quantitative methods is most likely to be associated with an ontological stance of 'realism', with a 'positivist' epistemology. Positivists face the world impartially to discover absolute knowledge about an objective reality, and it is said the researcher and the research are independent entities (Scotland, 2012).

Qualitative research is most often associated with an ontological stance of 'relativism', with the view that reality is subjective, and there are as many realities as there are individuals (Scotland, 2012). The epistemology of qualitative research is typically 'interpretive' which suggests the social world and the researcher will inevitably influence one another, which makes value-free objective research impossible (Snape & Spencer, 2003).

'Purists' may argue that as quantitative and qualitative research methods have different ontologic and epistemologic assumptions, the two cannot and should not be mixed (Onwuegbuzi & Leech, 2005). However, Purists can focus on the differences between quantitative and qualitative methodology and neglect to appreciate the similarities. For example, data-reduction is typically important for data

analysis processes in both quantitative and qualitative methodologies, and it could be argued that factors from statistical factor analysis are equivalent to emergent themes from thematic analyses (Onwuegbuzi & Leech, 2005).

Fundamentally, meaning is developed from the interpretation of data, whether represented by numbers or words (Onwuegbuzi & Leech, 2005).

As opposed to Purists, 'Pragmatists' maintain that there is a false dichotomy between the two methodologies (Newman & Benz, 1998), and promote the integration of methods within single studies to utilise the strengths of both (Onwuegbuzi & Leech, 2005).

Regarding this thesis and my personal epistemological stance, I believe I am a Pragmatist; not fully ascribing to either the Positivist or Interpretivist viewpoint. Within the empirical study of this thesis, the main aim was to investigate the relationship between the information communicated in diagnostic disclosure and quality-of-life and whether Illness Perceptions influenced this. Beginning this research process my strengths and interests as a researcher favoured quantitative methodologies, and the Positivist tradition of aiming to understand a larger quantity of individuals. It was also important for me to consider time confines, as well as my own strengths in, and experience of, research methodologies. While the empirical paper was based in theory with quantitative measurable concepts, it also felt exploratory in nature due to its originality. Due to this and my Pragmatic stance, the strengths and weaknesses of both quantitative and qualitative methods were considered. Both methodologies could be seen as equally beneficial in this

circumstance, and due to this and my Pragmatist stance I wanted to be flexible to the available techniques.

Not being fully affiliated with the Positivist viewpoint has allowed me to be mindful that I am not measuring 'the truth' through this research. For example, while I believe quantitative questionnaires can be interpreted objectively, I would also consider that individual participants are likely to subjectively interpret the questions and concepts being measured. For example, the concepts being measured in the empirical study, particularity quality-of-life, will undoubtedly be viewed differently by each individual participant, so I have remained aware that the definitions and ideas included in the measures in this study are not absolute; as expressed in my empirical discussion. Additionally, it is unlikely that these measures could have been developed without the researcher's perspectives on the concept having an impact.

The above led to the decision to choose a predominantly quantitative method with a smaller qualitative element included in the empirical study. It was believed the qualitative element would allow participants to express their thoughts and experiences on the concepts being measured which were not, or could not, be captured in quantitative measures. Additionally, this may highlight areas of importance which are neglected in the questionnaires. Data from this qualitative component offered validation for the quantitative data in an emotive and personalised fashion which could not have been achieved solely through numbers. Furthermore, this allowed hypotheses to be formed regarding why certain statistical relationships were not found.

Due to the mixed methodologies design, thematic analysis was chosen to analyse qualitative data as Braun and Clarke (2006) state this can be applied across a range of theoretical and epistemological approaches. Semantic level analysis was chosen, looking only at what participants reported in order to develop themes, rather than latent analysis which would involve looking further into the data at the language used.

Braun and Clarke (2006) also distinguish between inductive and deductive approaches when identifying themes. An inductive approach is led by the data itself, whereas a deductive approach involves the use of a pre-defined theory to guide coding. While this study was underpinned by the theory of the concepts being measured, the aim of the qualitative aspect was not to categorise participants responses by these concepts, but rather to analyse the data inductively to explore what developed into important themes for this group of people.

To summarise, whilst initially favouring a Positivist epistemological position, this thesis is underpinned by a Pragmatic perspective; emphasising the value of both quantitative and qualitative research methodologies. The incorporation of both methodologies in a single study has been suggested as the most beneficial approach to research (Onwuegbuzie & Leech, 2005). I believe these have complemented and supported each other well in this thesis, and together were able to explore experiences that one methodology could not obtain alone.

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Appendix B: Submission Guidelines for the *International Journal of Clinical Practice*

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b. Abstract

Original research, systematic reviews, and metaanalyses require structured abstracts. The abstract should provide the context or background for the study and should state the study's purpose, basic procedures (selection of study participants, settings, measurements, analytical methods), main findings (giving specific effect sizes and their statistical and clinical significance, if possible), and principal conclusions. It should emphasize new and important aspects of the study or observations, note important limitations, and not overinterpret findings. Clinical trial abstracts should include items that the CONSORT group has identified as essential (www.consort-statement.org/resources/downloads/extensions/consort-extension-for-abstracts-2008pdf/). Funding sources should be listed separately after the Abstract to facilitate proper display and indexing for search retrieval by MEDLINE.

Because abstracts are the only substantive portion of the article indexed in many electronic databases, and the only portion many readers read, authors need to ensure that they accurately reflect the content of the article. Unfortunately, information in abstracts often differs from that in the text. Authors and editors should work in the process of revision and review to ensure that information is consistent in both places. The format required for structured abstracts differs from journal to journal, and some journals use more than one format; authors need to prepare their abstracts in the format specified by the journal they have chosen.

The ICMJE recommends that journals publish the clinical trial registration number at the end of the abstract. The ICMJE also recommends that, when a registration number is available, authors list that number the first time they use a trial acronym to refer to the trial they are reporting or to other trials that they mention in the manuscript. If the data have been deposited in a public repository, authors should state at the end of the abstract the data set name, repository name and number.

c. Introduction

Provide a context or background for the study (that is, the nature of the problem and its significance). State the specific purpose or research objective of, or hypothesis tested by, the study or observation. Cite only directly pertinent references, and do not include data or conclusions from the work being reported.

d. Methods

The guiding principle of the Methods section should be clarity about how and why a study was done in a particular way. The Methods section should aim to be sufficiently detailed such that others with access to the data would be able to reproduce the results. In general, the section should include only information that was available at the time the plan or protocol for the study was being written; all information obtained during the study belongs in the Results section. If an organization was paid or otherwise contracted to help conduct the research (examples include data collection and management), then this should be detailed in the methods.

The Methods section should include a statement indicating that the research was approved or exempted from the need for review by the responsible review committee (institutional or national). If no formal ethics committee is available, a statement indicating that the research was conducted according to the principles of the Declaration of Helsinki should be included.

i. Selection and Description of Participants

Clearly describe the selection of observational or experimental participants (healthy individuals or patients, including controls), including eligibility and exclusion criteria and a description of the source population. Because the relevance of such variables as age, sex, or ethnicity is not always known at the time of study design, researchers should aim for inclusion of representative populations into all study types and at a minimum provide descriptive data for these and other relevant demographic variables. If the study was done involving an exclusive population, for example in only one sex, authors should justify why,

except in obvious cases (e.g., prostate cancer).” Authors should define how they measured race or ethnicity and justify their relevance.

ii. Technical Information

Specify the study’s main and secondary objectives— usually identified as primary and secondary outcomes. Identify methods, equipment (give the manufacturer’s name and address in parentheses), and procedures in sufficient detail to allow others to reproduce the results. Give references to established methods, including statistical methods (see below); provide references and brief descriptions for methods that have been published but are not well-known; describe new or substantially modified methods, give the reasons for using them, and evaluate their limitations. Identify precisely all drugs and chemicals used, including generic name(s), dose(s), and route(s) of administration. Identify appropriate scientific names and gene names.

iii. Statistics

Describe statistical methods with enough detail to enable a knowledgeable reader with access to the original data to judge its appropriateness for the study and to verify the reported results. When possible, quantify findings and present them with appropriate indicators of measurement error or uncertainty (such as confidence intervals). Avoid relying solely on statistical hypothesis testing, such as P values, which fail to convey important information about effect size and precision of estimates. References for the design of the study and statistical methods should be to standard works when possible (with pages stated). Define statistical terms, abbreviations, and most symbols. Specify the statistical software package(s) and versions used. Distinguish prespecified from exploratory analyses, including subgroup analyses.

e. Results

Present your results in logical sequence in the text, tables, and figures, giving the main or most important findings first. Do not repeat all the data in the tables or figures in the text; emphasize or summarize only the most important observations. Provide data on all primary and secondary outcomes identified in the Methods Section. Extra or supplementary materials and technical details can be placed in an appendix where they will be accessible but will not interrupt the flow of the text, or they can be published solely in the electronic version of the journal.

Give numeric results not only as derivatives (for example, percentages) but also as the absolute numbers from which the derivatives were calculated, and specify the statistical significance attached to them, if any. Restrict tables and figures to those needed to explain the argument of the paper and to assess supporting data. Use graphs as an alternative to tables with many entries; do not duplicate data in graphs and tables. Avoid nontechnical uses of technical terms in statistics, such as “random” (which implies a randomizing device), “normal,” “significant,” “correlations,” and “sample.”

Separate reporting of data by demographic variables, such as age and sex, facilitate pooling of data for subgroups across studies and should be routine, unless there are compelling reasons not to stratify reporting, which should be explained.

f. Discussion

It is useful to begin the discussion by briefly summarizing the main findings, and explore possible mechanisms or explanations for these findings. Emphasize the new and important aspects of your study and put your findings in the context of the totality of the relevant evidence. State the limitations of your study, and explore the implications of your findings for future research and for clinical practice or policy. Do not repeat in detail data or other information given in other parts of the manuscript, such as in the Introduction or the Results section.

Link the conclusions with the goals of the study but avoid unqualified statements and conclusions not adequately supported by the data. In particular, distinguish between clinical and statistical significance, and avoid making statements on economic benefits and costs unless the manuscript includes the appropriate economic data and analyses. Avoid claiming priority or alluding to work that has not been completed. State new hypotheses when warranted, but label them clearly.

Appendix C: Data Extraction Form for Systematic Literature Review

Data Extraction Form

Author

Year

Journal

Country

Sample

N

Profession

Cancer site

Setting

Method

Results

Preference of disclosure

Components of preference

Appendix D: Quality Checklist for Systematic Literature Review

Quality Assessment Checklist

Adapted from **STROBE** (Vandenbroucke et al., 2007), **Downs and Black** (1998), and the **Mixed Methods Appraisal Tool** (MMAT; Pluye et al., 2011).

The items not colour coded were not affiliated to any of the above checklists. These were included by the chief reviewer (FSE) after initial review of the final articles as it was deemed these aspects were important to assess for quality.

Article Section	Item No	Criteria	Score				N/A
			Yes 2	Partly 1	No 0	Unclear 0	
Introduction							
Background/rationale	1	Is the scientific background and rationale for the investigation explained?					
Objectives	2	Is the hypothesis/aim/objective clearly described?					
Methods							
Study design	3	Are key elements of study design presented? (type of design, methods, procedure etc.)					
Setting	4	Are the settings, locations, and relevant dates, including periods of recruitment and data collection, described?					
Participants	5	(a) Are the eligibility criteria, and the sources and methods of selection of participants clearly described?					
		(b) Are participant demographics reported?					
		(c) Is the profession of participants reported?					
		(d) Is type of cancer reported?					

Sample	6	(a) Is it explained how the study size was arrived at?					
		(c) Is the sample representative of the population under study?					
Measures	7	Are measures appropriate (clear origin, or validity known, or standard instrument)?					
Outcomes	8	Are main outcomes to be measured clearly described?					
Statistical methods	9	(a) Are all statistical methods described?					
		(b) Were the statistical tests used to assess the main outcome appropriate?					
Results							
Participants	10	(a) Reports numbers of individuals at each stage of study—e.g. numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, and analysed.					
		(b) Is there an acceptable response rate (60% or above)?					
Descriptive data	11	Indicates number of participants with missing data for each variable of interest					
Main results	12	(a) Are the main findings clearly described?					
		(b) Gives unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders					

		were adjusted for and why they were included					
		(c) Are directions of preference components/influences clearly stated?					
		(d) Are P values stated?					
Continuity	13	Does information in tables and text match?					
Discussion							
Key results	14	Summarises key results with reference to study objectives.					
Limitations	15	Discusses limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.					
Interpretation	16	Gives a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.					
Generalisability	17	Is the generalisability (external validity) of the study results discussed?					
Totals							

Other Notes:

Total Score =

Divided by total possible score (52) =

X 100 =

Appendix E: Submission Guidelines for *Neuro-Oncology Practice*

MATERIAL DISCLAIMER

The opinions expressed in *Neuro-Oncology Practice* are those of the authors and contributors and do not necessarily reflect those of the Society, the editors, the editorial board, Oxford University Press, or the organization to which the authors are affiliated.

Manuscript Submission

Submittal of a manuscript to *Neuro-Oncology Practice* implies that the authors of the paper understand and fully accept the policies of the journal as detailed in these Instructions to Authors. Please read these instructions carefully and follow them strictly to ensure that the review and publication of your paper is as efficient and quick as possible. The editors reserve the right to return manuscripts that are not in accordance with these instructions.

All manuscripts submitted for possible publication, including text, tables, graphics, and supplementary materials, should be submitted online via the journal's online submission system at <https://www.editorialmanager.com/nop>. Once you have prepared your manuscript according to the instructions below, please read our instructions on how to submit your manuscript online here. If you have any problems with the submission process or any questions about the guidelines in these instructions, please contact the *Neuro-Oncology Practice* editorial office at nop.editorialoffice@oup.com

Review of Manuscripts

Papers will normally be reviewed within 4 weeks of submission. Authors may suggest appropriate reviewers to whom the manuscript could be assigned or stipulate those reviewers who may have a bias or conflicting interest. Full addresses, including mail and e-mail addresses, and telephone and fax numbers of suggested reviewers should be provided. Final assignments, however, are at the discretion of the Editor in Chief. Manuscripts and illustrations are not returned to the author unless the author requests them. Journal policy dictates that the identity or information leading to the identity of any reviewer is not to be revealed.

Types of Articles Published

The following types of unsolicited articles are published in *Neuro-Oncology Practice*:

- *Clinical Investigations* that report original experimental, clinical, translational, epidemiological, quality-of-life, or other studies relating to neuro-oncology practice and that are well documented, novel, and significant; included in this group are Phase 1–4 clinical trials reports.
- *Reviews and Editorials* that cover subjects of timely interest and importance to cancer clinicians and health care professionals. (These are written by invitation of the Editor in Chief. Authors wishing to write a review or an editorial should send a letter to the Editor in Chief outlining the proposed article. All reviews, invited or uninvited, will be peer reviewed.)
- *Letters to the Editor* offering considered opinions on manuscripts published in the journal within the last 6 months (correspondence concerning articles that have not been published in *Neuro-Oncology Practice* will not be considered). Letters containing brief results or

technical notes of interest to the neuro-oncology community may also be considered for publication.

- *Case Studies* are brief, without an extensive review of the literature, and Case Illustrations contain briefly written text and references and portray, by neuroimaging, those concepts better visualized than described. Case Studies and Case Illustrations are only rarely published in *Neuro-Oncology Practice*, and authors are discouraged from submitting them except when the case is of extraordinary importance.

The following types of articles typically are solicited by the Editor in Chief:

- *Symposia* on subjects selected by the Editor in Chief
- *Invited Meeting Reports* selected and invited by the Editor in Chief
- *Book Reviews* by invitation of the Editor in Chief (if you are interested in reviewing books for *Neuro-Oncology Practice*, please contact the Editorial Office)

Format

No manuscript will be sent out for review until all items are received. The preferred software for text is Microsoft Word, although manuscripts generated in other word processing programs are acceptable if saved in Rich Text Format. Papers prepared using desktop publishing software are not acceptable. The preferred software for illustrations is described in the Figures & Illustrations section.

The manuscript text (title page, abstract, article text, acknowledgments, reference list, and figure captions), figures, and tables (in .doc or .rtf format) should be submitted as separate files. This applies to the original version of the manuscript and any revised versions.

Please use short, simple filenames when saving all your documents and avoid special characters, punctuation marks, symbols (such as &), and spaces. Macintosh users must also type the extension at the end of the file name (.doc, .rtf, .jpg, .gif, .tif, .xls, .pdf, .eps, .ppt, .mov, or .qt).

Other helpful hints are: (i) use the TAB key once for paragraph indents; (ii) where possible, use Times New Roman for the text font and Symbol for any Greek and special characters; (iii) use word processing formatting features to indicate **Bold**, *Italic*, Greek, Math, superscript, and subscript characters; (iv) please avoid using underline: for cases, use italic; for emphasis, use bold; (v) clearly identify unusual symbols and Greek letters; and (vi) differentiate between the letter O and zero and among capital I, lowercase L, and the number 1.

Footnotes should not be used in the text.

At the time of submission, please also include the files for any supplementary material that should accompany your manuscript.

Double-space the entire manuscript (including references, tables, figure captions, and

supplementary materials) on U.S. letter-sized paper, leaving at least 1-inch (2.54-cm) margins all around and set to print on one side of the paper only. Manuscripts should conform strictly to journal style. Those not in *Neuro-Oncology Practice* style (described below) or not written in good idiomatic U.S. English may be returned to the author without review. Terminology and abbreviations not consistent with internationally accepted guidelines should be avoided (see Abbreviations & Acronyms below), as should laboratory jargon.

It is recommended that authors spell-check (with the language set to U.S. English) all files before submission. Particularly if English is not your first language, before submitting your manuscript, you may wish to have it edited for language. This is not a mandatory step but may help to ensure that the academic content of your paper is fully understood by journal editors and reviewers. Language editing does not guarantee that your manuscript will be accepted for publication. A list of such services is provided here. Other specialist language editing companies offer similar services. Authors are liable for all costs associated with such services.

Style guides that may be helpful in writing the manuscript are the current editions of the *American Medical Association Manual of Style* and *The ACS Style Guide. Essentials of Writing Biomedical Research Papers, 2nd ed.* (M. Zeiger, ed., McGraw Hill, 2000) which addresses the content and format of scientific articles. Authors are urged to proofread and edit their manuscripts carefully before submittal. Alterations at the proof stage delay publication and are expensive. Excessive changes at the proof stage not due to printer's errors will be charged to the authors.

Arrange the sections of text in the following order, and number all pages, beginning with the title page:

- Title page
- Abstract and keywords
- Text
- Acknowledgments
- References
- Captions for all illustrations
- Tables (these must be submitted as separate files)

Basic format for articles

The basic format for original articles, including reports of clinical trials is described here. Articles with unique formatting requirements (case studies, case illustrations, review articles, and invited meeting reports) are covered below.

Title page

- Title
- Authors' full names

- Affiliation of each author at the time of the study, including complete addresses, with zip codes. If authors are from more than one department or institution, each author's initials should be placed in parentheses after the applicable address.
- Running title, not to exceed 50 characters and spaces
- Name and contact information for the corresponding author, including telephone, fax, and e-mail address
- Footnotes regarding change of address or affiliation, co-first authorship, or new sequence accession numbers
- Statement (titled "Funding") detailing any funding that supported the research
- Statement (titled "Conflict of interest") detailing any conflicts of interest for all authors
- List of any unpublished papers cited (see Unpublished Material under References)
- If applicable, a statement that the paper being submitted is one of a series

Any deletions or additions to the author list after acceptance of the paper must be submitted in writing or by email, signed by all authors (including those added or deleted), to the *Neuro-Oncology Practice* editorial office. Publication of manuscripts will be withheld until all such written approvals are received. *Neuro-Oncology Practice* accepts no responsibility for such changes.

Similarly, all conflicts of interest (or relationships that would be suspected of constituting conflicts) should be declared and explained at the time of submission and reflect not only current conflicts but those in place at the time the research was conducted. Any changes made to the list of conflicts after the paper is accepted must be submitted in writing, signed by the appropriate authors (that is, the corresponding author and the author for whom the conflict exists), to the *Neuro-Oncology Practice* editorial office. Publication of manuscripts will be withheld until all such written approvals are received. *Neuro-Oncology Practice* accepts no responsibility for such changes.

Authorship

All authors listed on the manuscript should have contributed significantly to the experimental design, its implementation, or analysis and interpretation of the data. All authors should have been involved in the writing of the manuscript at draft and any revision stages, and have read and approved the final version. Any other individuals who contributed to the experiment or the writing of the manuscript should be listed in the Acknowledgment section.

Authorship Requirements. For guidelines on authorship, please refer to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, formulated by the International Committee of Medical Journal Editors. The cover letter should state that all authors have seen and approved the manuscript.

Abstract

The abstract should not exceed 250 words. All abstracts, except those accompanying review articles and case series should be written in structured format:

- **Background:** State the clinical (or other) importance of the work. Include a hypothesis or

purpose statement (e.g., “To determine whether..., we...”).

- **Methods:** Give the materials (or patients) and methods used to answer the research question.
- **Results:** State the study’s findings. Make sure the results match the methods.
- **Conclusions:** In a sentence or two, explain how the findings address the purpose of the study. The conclusions should be supported by the results given.

Because abstracts often appear apart from the text of a paper (e.g., in PubMed or Medline), they should not cite references. Keep nonstandard abbreviations and acronyms to a minimum (no more than five in the abstract), defining them in parentheses at first mention. It is essential that the Abstract clearly states the biological importance of the work described in the paper.

Keywords

Below the abstract, list up to five keywords that may be used for indexing.

Text

NEW: The word limit for entire text of original articles, including abstract, main text body, references, and figure legends is **7000 words**.

Introduction. This section should state the problem or question being addressed and summarize relevant background information to provide context for the research question.

Materials and Methods. The explanation of the experimental methods should be brief but adequate for repetition by qualified investigators. Procedures that have been published previously should merely be cited in appropriate references. Only new and significant modifications of previously published procedures need complete exposition. The sources and manufacturers of special chemicals or preparations used should be named.

Results. This section should include a concise summary of the data presented in the tables and illustrations. Excessive elaboration of those data should be avoided. The Results and Discussion sections may be combined if doing so saves space or improves the logical sequence of the material.

Discussion. The data should be interpreted concisely, without repeating material already presented in the Results section. Speculation is permissible, but it must be well founded and clearly identified as speculation.

For experimental investigations of human subjects, state in the Methods section of the manuscript that an appropriate institutional review board approved the project. Investigators who do not have formal ethics review committees should follow the principles outlined in

World Medical Association Declaration of Helsinki: Research involving human subjects

Statistical methods should also be clearly and completely described in the Methods section.

Funding. Details of all funding sources for the work in question should be given in a separate section entitled "Funding". This should appear before the "Acknowledgments" section. The following rules should be followed: the full official funding agency name should be given (that is, "National Institutes of Health", not "NIH"); grant numbers should be given in brackets; multiple grant numbers should be separated by a comma; agencies should be separated by a semi-colon; no extra wording such as "Funding for this work was provided by ..." should be used; where individuals need to be specified for certain sources of funding, explanatory text should be added after the relevant agency or grant number "to [author initials]" (e.g., "National Institutes of Health (CB5453961 to C.S., DB645473 to M.H.); Funding Agency (hfygr667789).")

Acknowledgments (optional). An Acknowledgments section (not footnotes) should be included, if appropriate, to recognize the following:

- Special assistance or contributions by non-authors (e.g., supply of materials or editorial support)
- Financial support for the research or a researcher (specifying grant numbers and recipients) other than that described in the Funding state

Personal acknowledgments should precede those of institutions or agencies. Please note that acknowledgment of funding bodies and declarations regarding conflict of interest should be given in separate Funding and Conflict of Interest sections on the title page (see above).

References. See "References" for specific instructions.

Figure Captions and Tables. Figures should be numbered sequentially with Arabic numerals. Figures may have subparts (A, B, C, etc.); each subpart should be described in the caption. See recent issues of the journal for examples of acceptable styles.

NEW: There is a limit of 6 display items (tables or figures) for original articles.

Captions are required for all figures and should be typed, double-spaced, after the list of references. Captions should briefly describe the data shown and should not repeat details given in the text. Include the type of staining, magnification, and similar information required for accurate interpretation where applicable. Each caption should adequately identify all symbols (where not defined on the figure itself) and abbreviations used in the figure. Captions and symbols should make the figure interpretable without reference to the text. Figure numbers or captions should not be included on the face of an illustration.

Number tables with Arabic numerals. Tabular material should not simply duplicate data presented in the text or figures. Large groups of individual values should be avoided; instead, these should be averaged and an appropriate designation of the dispersion, such as standard deviation or standard error, included.

Tables should be typed in the manuscript file format with double spacing, but minimizing redundant space; tables must be submitted as separate files and include a descriptive title. Note that each column, including the first column, must carry an appropriate heading, and if numerical measurements are given, these units should be added to the column heading.

Identify footnotes with superscript lowercase italic letters (*a, b, c, etc.*). Tables should not have subparts.

Special formatting requirements for other articles

Clinical Study Reports are formatted like clinical investigations. However, before submitting a clinical study report, authors should consult the GNOSIS guidelines (published in the October 2005 issue of *Neuro-Oncology Practice* [Vol. 7, Issue 4] [PDF]) and, to ensure completeness, crosscheck their manuscript against these guidelines. For negative studies, authors are asked to limit reports to no more than, and preferably fewer than, 18 typed pages, including title page, text, references, and tables and figures.

Case Studies and Case Illustrations must be brief—typically no more than 4 printed pages (about 12 double-spaced pages, including references and illustrations)—and should normally contain no more than 25 references.

Review Articles have a more open format than do other article types. Because of the nature of review articles, which may cover a broad scope of topics related to the subject at hand, authors should use short headings to identify major manuscript sections. Though potentially broad in scope, reviews should be as concise as possible and should focus on seminal findings and important developments contributing to understanding of (or controversy about) the subject at hand. Accordingly, the number of references for review articles should be kept as small as possible (typically, no more than 100 is sufficient). **New:** Review articles should have no more than 8000 words for all sections, including abstract, main text body, references, and figure legends. There is also a maximum of 7 display items (figures or tables).

Invited Meeting Reports should typically have a total length—including the title page, text, references, and tables or figures—of five printed pages (or about 15 typed pages).

null

References

If you use EndNote and Reference Manager to facilitate referencing citations (not required for submission), this journal's style is available for use.

Neuro-Oncology Practice uses a numbered reference list, with references presented in order of citation in the text; superscript Arabic numbers are used to cite references in the text.

Within the reference list at the end of the paper, please follow the format shown in the samples below. Note that the author's surname and initials (without commas or periods) are used. In accordance with the current edition of the AMA Manual of Style, for works with more than six authors, list the first three authors and then "et al.": Rose PR, Walker BK, Matthews CP Jr, et al. The issue number should be mentioned in parentheses following the volume number.

Sample reference entries:

• Journal Article

1. Gottardo NG, Gajjar A. Chemotherapy for malignant brain tumors of childhood. *J Child Neurol.* 2008; 23(10): 1149-1159.

• Correction

1. Apte SS, Olsen BR, Murphy G. The gene structure of tissue inhibitor of metalloproteinases (TIMP)-3 and its inhibitory activities define the distinct TIMP gene family [published correction appears in *J Biol Chem.* 1996;271:2874]. *J Biol Chem.* 1995;270:14313–14318.

• Supplement

1. Robins HI, Peterson CG, Mehta MP. Combined modality treatment for central nervous system malignancies. *Semin Oncol.* 2003;30(suppl.):11–22.

• Chapter in Book

1. Bailey OT. Medulloblastoma. In: Minckler J, ed. *Pathology of the Nervous System.* Vol. 2. New York: McGraw-Hill; 1971:2071–2081.

• Book

1. Kaye AH, Laws ER Jr, eds. *Brain Tumors: An Encyclopedic Approach.* Edinburgh: Churchill Livingstone; 1995.

• Web References

1. Children's Memorial Hospital. (2010) First children's hospital in Illinois to acquire new device for pediatric brain and spine tumor removal. Available at <http://www.childrensmemorial.org/newsroom/release06022010.aspx>. Accessed June 21, 2010.

2. OMIM. Online Mendelian Inheritance in Man Database. Available at <http://www.ncbi.nlm.nih.gov/omim>. Accessed February 28, 1998.

• Abstract

1. Vaidyanathan G, Friedman HS, Keir ST, Zalutsky, MR Meta-[211At]astatobenzylguanidine (MAbs): in vivo evaluation in an athymic mouse human neuroblastoma xenograft model [abstract]. *J Nucl Med.*

• Unpublished Material

Cite unpublished articles (including those in review or preparation), data, and observations parenthetically in the text as either “unpublished data” or “unpublished manuscript,” along with the name of the investigator responsible for those data (e.g., the lead author of a paper in preparation). No manuscript title or presumed year of publication is needed. In the case of “personal communications,” give the name of the original speaker/correspondent and, if possible, the date of the communication; note that the Editorial Office requires a signed statement from the speaker/correspondent giving the author permission to quote him or her in the manuscript. (Example: Nonetheless, it appears that peptides become associated in some fashion with chaperones prior to or upon extraction from cells (M.W. Graner, unpublished data), and the effects of exogenous chaperones on the innate immune cells are certainly not denied.)

Abbreviations and Acronyms

Genes: All gene names should be in italic type, while their corresponding proteins should appear in roman type. For human gene names, the Human Genome Organisation's

database style (all caps, no hyphens) and name (not alias) are used. Visit the OMIM database for human protein terminology.

Other: Nonstandard abbreviations should be kept to a minimum. They should be defined at the first occurrence and introduced only when the abbreviation will be used several times. The term “nonstandard” refers to abbreviations that are not a part of the *Système International d’Unités* (International System of Units, known as SI units) and those that are not widely known. Some standard abbreviations not needing expansion at first use are listed in the current edition of the *AMA Manual of Style*. A list of standard abbreviations is also included at the end of these instructions. Nonstandard abbreviations used in a manuscript should be established in parentheses when they are first mentioned in the text (e.g., “The study population was drawn from the institution’s neonatal intensive care unit (NICU) . . .”).

Abbreviations list.

Authors may use, without definition, the following abbreviations:

ADP adenosine diphosphate
ATP adenosine triphosphate
cDNA complementary DNA
CNS central nervous system
CoA, acyl-CoA coenzyme A and its acyl derivatives (e.g., acetyl)
CT computed tomography
DNA deoxyribonucleic acid
DNase deoxyribonuclease
EDTA ethylenediaminetetraacetate
ELISA enzyme-linked immunosorbent assay
FDA Food and Drug Administration (U.S.)
IR infrared
KPS Karnofsky performance status
MR magnetic resonance
MRI magnetic resonance imaging
mRNA messenger RNA
NAD⁺, NADH nicotinamide adenine dinucleotide and its reduced form
NADP⁺, NADPH nicotinamide adenine dinucleotide phosphate and its reduced form
NCI National Cancer Institute (U.S.)
NIH National Institutes of Health (U.S.)
nRNA nuclear RNA PCR polymerase chain reaction
PET positron emission tomography
RBC red blood cell
RNA ribonucleic acid
RNase ribonuclease
rRNA ribosomal RNA
tRNA transfer RNA
Tris tris(hydroxymethyl)methylamine
UV ultraviolet

WBC white blood cell
WHO World Health Organization

Units of Concentration:

Gy gray
M (not used for moles) molar (moles/liter)
mM (preferred to 10^{-3} M) millimolar (millimoles/liter)
 μ M (preferred to 10^{-6} M) micromolar (micromoles/liter)
nM (not mM) nanomolar
pM (not mM) picomolar
g/ml, g/100 ml, g per liter, etc. avoid using mg%

Units of Length, Area, Volume, Mass, Time:

The abbreviations below are correct for both singular and plural forms of each term.

cm centimeter
g gram
h hour
kg kilogram
m meter
min minute
 μ m micrometer (not micron)
mm millimeter
ml milliliter
 μ l microliter
 μ g microgram
mg milligram
nm nanometer
pm picometer
s second

Physical and Chemical Units:

$^{\circ}$ C degree Celsius (centigrade)
 $^{\circ}$ F degree Fahrenheit
g acceleration of gravity (closed with number [e.g., 200g])
K Kelvin

Others:

Ci Curie
cpm counts per minute
Da dalton
dpm disintegrations per minute
eq equivalent log logarithm (Briggsian)
ln logarithm (natural)
mol mole
Mr molecular weight
P probability

R roentgen
rpm revolutions per minute
S Svedberg unit
SD standard deviation
SEM standard error of the mean
V volt

In chemical compounds:

o- ortho
m- meta
p- para
sec- secondary
tert- tertiary

Routes of administration:

i.c. intracranial
i.m. intramuscular
i.p. intraperitoneal
i.v. intravenous
p.o. oral
s.c. subcutaneous

Tables

All tables should be on separate pages and accompanied by a title and footnotes where necessary. The tables should be numbered consecutively using Arabic numerals. Units in which results are expressed should be given in parentheses at the top of each column and not repeated in each line of the table. Ditto signs are not used. Avoid overcrowding tables and using excessive text. The format of tables should be in keeping with that normally used by the journal; in particular, vertical lines, colored text, and shading should not be used. Please be certain that the data given in tables are correct.

Figures and Illustrations

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Appendix F: Ethical approval

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Appendix G: Online Advertisement Poster

Illness Perceptions and Quality of Life in Brain Tumours:

Does Diagnostic Communication have an Impact?

Participants Needed!

This research is looking at illness perceptions. These are a set of beliefs that people develop to make sense of their symptoms and condition. Research has suggested that people's perceptions of their illness vary, even between those with similar illnesses. People can build their illness perceptions based in part on previous personal or family experiences with their illness, or information they may have received from medical staff or the general media. Numerous previous studies have demonstrated a link between illness perceptions and their quality of life. Quality of life is one way of looking at people's wellbeing, and how they experience living with a medical condition.

This research is interested in whether people's illness perceptions are affected by how the diagnosis of a brain tumour is communicated to them, and in turn whether their illness perceptions affect their quality of life.

Who can take part? You are eligible to take part if you:

1. Have been diagnosed with a primary brain tumour,
2. Are aged 18 years or over,
3. Can read and write/type in English.

What is involved if I volunteer?

Volunteers will be asked to read a page of information about the research, informing them about the benefits and potential risks of taking part. Volunteers who decide to take part after reading this will complete an online questionnaire, as well as a short demographic questionnaire. This could take 20-30 minutes. Volunteers are free to read the study information and complete the questionnaire at a time and place that is convenient for them.

How do I volunteer?

You can read the information and complete the questionnaires online via: <https://hull.onlinesurveys.ac.uk/braintumourresearch>

Please note, this questionnaire will close in December 2015

For more information please contact Francesca Smithson Evans, Researcher and Trainee Clinical Psychologist, at f.smithson-evans@2013.hull.ac.uk. You can also contact Dr Emma Wolverson at E.Wolverson@hull.ac.uk or Dr Catherine Derbyshire at Catherine.Derbyshire@hey.nhs.uk (Research Supervisors and Clinical Psychologists).

Thank you for your interest!

Appendix H: Information sheet, Consent Form, and Empirical Questionnaire

Illness Perceptions And Quality Of Life In Brain Tumours: Does Diagnostic Communication Have An Impact?

Welcome

Information Sheet

Name of Researcher: Francesca Smithson Evans

We would like to invite you to participate in our research. This is investigating how people living with a brain tumour view their condition, how they rate their quality of life, and whether the way in which their diagnosis was communicated affects these.

Before you decide if you would like to take part, we would like to explain the purpose and aims of the research, and what participation would involve. If you have any questions about the study, you can contact the researcher using the details at the end of the information sheet.

What Is The Purpose Of The Research?

This research is looking at illness perceptions. These are a set of beliefs that people develop to make sense of their symptoms and condition. Research has suggested that people's perceptions of their illness vary, even between those with similar illnesses. People can build their illness perceptions based in part on previous personal or family experiences with their illness, or information they may have received from medical staff or the general media. Numerous previous studies have demonstrated a link between people's illness perceptions and their quality of life. Quality of life is one way of looking at people's wellbeing, and how they experience living with a medical condition.

This research is interested in whether people's illness perceptions are affected by how the diagnosis of a brain tumour is communicated to them, and in turn whether their illness perceptions effect their quality of life.

Why Have I Been Invited To Take Part?

1 / 24

The details of this research have been sent to brain tumour support charities across the UK, Canada, and Australia. The study is open to anyone who has a primary brain tumour, are at least 18 years old, and can read and type in English.

Do I Have To Take Part?

No, participation is completely voluntary. If you decide to take part you will be asked to give your consent by ticking a few boxes on the online survey tool to indicate that you agree to take part. You are free to withdraw from the study at any point while completing the questionnaire, your answers will not be saved, and you do not have to give a reason for this. There is also the option to 'finish later' on each page. However, if you just click off the survey window your answers will not be saved. Once you have completed the survey you will not be able to withdraw your data, as this is all anonymous so your answers cannot be identified. Participation will not affect your medical care or your legal rights.

What Will I Need To Do If I Decide To Take Part?

If you wish to take part, this will involve completing an online questionnaire, as well as providing some basic information about yourself, such as age, gender, ethnic group etc. There will also be the opportunity at the end of the questionnaires for you to share some additional thoughts or experiences in written format if you wish (however, this is not mandatory). As this will all be done online, you can complete this wherever, and whenever convenient to you. The whole process should take between 20-30 minutes to complete. Once you have finished, you have the option of printing your answers if you would like to keep a record of these. Please note, this questionnaire will close in December 2015.

What Are The Possible Disadvantages And Risks Of Taking Part?

Participating in the study will require up to thirty minutes of your time; this may be inconvenient for you. The questions require you think about getting your diagnosis and also about your current feelings towards your tumour, and your life in general since your diagnosis. It is possible that this may cause you some emotional distress. The names and contact details of helpful support organisations will be provided to all participants at the end of the study. This information will be given at the end of the questionnaire, or if you decide to finish sooner.

What Are The Possible Benefits Of Taking Part?

We cannot promise that you will have any direct benefits from participating in this research. We hoped that this research will help us understand more about living with a brain tumour, and whether the way people view their illness, and how they were communicated their diagnosis, can have an impact on this.

What If There Is A Problem?

If you have any concerns about any part of this study, you can contact the researcher or their research supervisors, who will do their best to answer your questions. Contact information is at the end of this information sheet.

Is It All Confidential?

All answers will be completely anonymous, and you will not be asked for information which could make you personally identifiable, such as your name or address. If you choose to give some additional thoughts or experiences in written format, quotes from this may be used in future publications, however they will be completely anonymous and you will not be able to be identified from them.

What Will Happen To The Results Of The Study?

After the study is completed the results from all participants will be analysed and presented in a report written for a scientific journal and as part of a thesis project. Results will also be presented at conferences and professional development events. A summary of the findings will be given to the organisations which have helped recruit for this study.

Who Is Organising And Funding The Research?

This research is being undertaken as part of a Doctoral thesis in Clinical Psychology. The research is funded and regulated through the University of Hull, UK. Some sections of data collected during the study that are relevant to participation may be assessed by responsible individuals from the University of Hull or from regulatory authorities to ensure that appropriate guidance was followed by the researcher.

Who Has Reviewed The Research?

This research has been reviewed by the University of Hull Research Ethics Committee and received a favourable review. This protects the interests of research participants.

If you have any further questions, comments, or queries please do not hesitate to contact Francesca Smithson Evans (Chief Investigator, contact information below).

Thank you for taking the time to read this information.

Yours Sincerely,

Francesca Smithson Evans
Trainee Clinical Psychologist

Supervised by

Dr Emma Wolverson
Clinical Psychologist

Dr Catherine Derbyshire
Macmillan Consultant Clinical Neuropsychologist

Contact Information

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Telephone: 01482 464170

If calling from Australia please dial 0011 44 1482 464170.

If calling from Canada please dial 011 44 1482 464170.

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Telephone: 01482 461076

*If calling from Australia please dial 0011 44 1482 461076.
If calling from Canada please dial 011 44 1482 461076.*

Consent Form

- I confirm that I am 18 years of age or older.
- I confirm I have read and understood the information sheet for the above study. I have had the opportunity to consider the information. If I had any questions, they have been answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time during the questionnaire, without my medical or legal rights being affected.
- I understand that once I have completed the questionnaire, I cannot withdraw my data from the study.
- I confirm that direct quotes from written responses may be used in future publications and understand these will be anonymous.
- I agree to take part in the above study.

Demographic Information

Please fill in the following demographic information about yourself.

Gender

Male
 Female

Age

How would you describe your ethnic group?

White
 Asian/Pacific Islander
 Black/African/Caribbean
 Hispanic/Latino
 Mixed/Multiple ethnic groups
 Other

If you selected Other, please specify:

How many years have you spent in education?

Occupation (Current or Previous)

Do you have any other active medical conditions?

Yes
 No

If yes, please state this here

Please tell us about your brain tumour...

	I	II	III	IV	Not Sure/Don't Know
Grade of Tumour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In what country did you receive your diagnosis?

UK
 Australia
 Canada
 Other

If you selected Other, please specify:

Which professional gave you your diagnosis?

- Neurosurgeon
- Neurologist
- Oncologist
- Other Medical Doctor
- Don't Know/Not Sure

If you selected Other, please specify:

If you would like to discontinue this questionnaire, please select the button below, which will take you to a list of support organisations. If you would like to continue, please go onto the next page.

- Discontinue

Diagnostic Communication

Please think about the time you were given your diagnosis of a brain tumour, and consider the following statements.

The Doctor explained the following to my satisfaction:

	Strongly Disagree	Disagree	Slightly Disagree	Not Sure	Slightly Agree	Agree	Strongly Agree
What my medical problem was.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The causes of my brain tumour.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
What my treatment options were.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The benefits and disadvantages of treatment choices .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The purpose of any tests that were needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How treatment could help my brain tumour.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to take prescribed medication.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The possible side effects from any medicine or treatment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The long-term consequences of my brain tumour.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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The Doctor did a good job of:

	Strongly disagree	Disagree	Slightly disagree	Not sure	Slightly agree	Agree	Strongly agree
Reviewing or repeating important information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making sure I understood his or her explanations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making sure I understood his or her directions/instructions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Checking his or her understanding of what I said.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encouraging me to ask questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking me questions related to my medical problem.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking me questions in a clear, understandable manner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asking questions that allowed me to elaborate on details.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using language I could understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being warm and friendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Contributing to a trusting relationship.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Showing he or she cared about me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making me feel relaxed or comfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Showing compassion.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being open and honest.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to discontinue this questionnaire, please select the button below, which will take you to a list of support organisations. If you would like to continue, please go onto the next page.

Discontinue

Your Views About Your Tumour

We are interested in your personal views and opinions about your brain tumour. Please answer the following questions by ticking the appropriate boxes.

	0 (No effect)	1	2	3	4	5	6	7	8	9	10 (Severely)
How much does your brain tumour affect your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (Not at all worried)	1	2	3	4	5	6	7	8	9	10 (Extremely worried)
How much are you worried your brain tumour will progress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (Absolutely no control)	1	2	3	4	5	6	7	8	9	10 (Totally in control)
How much control do you feel you have over your brain tumour?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (Not at all)	1	2	3	4	5	6	7	8	9	10 (Extremely helpful)
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much do you think your treatment can help your brain tumour?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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	0 (No symptoms at all)	1	2	3	4	5	6	7	8	9	10 (Many severe symptoms)
How much do you experience symptoms from your brain tumour?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (Not at all concerned)	1	2	3	4	5	6	7	8	9	10 (Extremely concerned)
How concerned are you about your brain tumour?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (Don't understand at all)	1	2	3	4	5	6	7	8	9	10 (Understand very clearly)
How well do you feel you understand your brain tumour?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	0 (No emotional effects)	1	2	3	4	5	6	7	8	9	10 (Extremely affected emotionally)
How much does your brain tumour affect you emotionally? (e.g. angry, scared, upset, or depressed?)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please list in rank-order the three most important factors you believe caused your brain tumour:

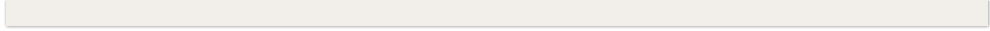
1)

2)

3)

If you would like to discontinue this questionnaire, please select the button below, which will take you to a list of support organisations. If you would like to continue, please go onto the next page.

 Discontinue



Quality of Life

Below is a list of statements that other people living with a brain tumour have said are important. Please select your response as it applies to the **past 7 days**.

Physical Wellbeing

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have a lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have nausea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Because of my physical condition, I have trouble meeting the needs of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am bothered by side effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am forced to spend time in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Social/Family Wellbeing

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel close to my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get emotional support from my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get support from my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

My family has accepted my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with family communication about my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel close to my partner (or the person who is my main support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with my sex life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Emotional Wellbeing

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with how I am coping with my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry about dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry that my condition will get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Functional Wellbeing

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work at home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My work (include work at home) is fulfilling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I am able to enjoy my life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have accepted my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am sleeping well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am enjoying the things I usually do for fun	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am content with the quality of my life right now	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Additional Concerns

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to concentrate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have had seizures (convulsions)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I can remember new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get frustrated that I cannot do the things I used to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am afraid of having a seizure (convulsion)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have trouble with my eyesight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have trouble hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to find the right word(s) to say what I mean	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

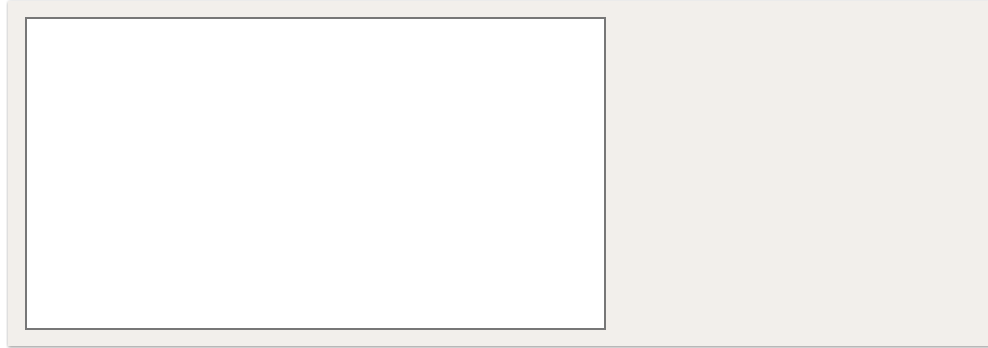
I have difficult expressing my thoughts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am bothered by the change in my personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to make decisions and take responsibility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am bothered by any drop in my contribution to the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to put my thoughts together	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I need help caring for myself (bathing, dressing, eating, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to put my thoughts into action	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to read like I used to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to write like I used to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to drive a vehicle (my car, truck, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have trouble feeling sensations in my arms, hands, or legs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have weakness in my arms or legs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have trouble with coordination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get headaches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you would like to discontinue this questionnaire, please select the button below, which will take you to a list of support organisations. If you would like to continue, please go onto the next page.

Discontinue

Additional Thoughts

Final Question- We now invite you to share any additional thoughts or experiences you have in relation to your diagnosis, how you view it, or it's affect on your life. Please write these is the space below. *Optional*

A large rectangular area for writing, consisting of a white box on the left and a shaded gray box on the right.

Support Services

Thank you for taking part in this research.

****Please click 'Finish' at the bottom of the page to save your responses****

If you would like support around your brain tumour diagnosis, you can contact the following organisations...

UK:

The Brain Tumour Charity, Support and Information Line- 0808 800 0004

This is a confidential telephone line, free from landlines and most mobiles, open from 9am to 5pm on weekdays. The line is run by their professional Support and Information team and is open for anyone to ask questions or talk about concerns. You can also email support@thebraintumourcharity.org or visit <http://www.thebraintumourcharity.org/support-information/Our-services>

Australia:

Brain Tumour Alliance Australia, Peer Support 1800 857 221.

Here, you can speak to someone who knows what it is like to travel the brain tumour journey. Please note, this number is answered on a person's private number, please inform the person who answers that you are inquiring about Brain Tumour Alliance Australia. You can also email, btsupport@btaa.org.au or visit <https://www.btaa.org.au/page/20/contact>

Canada:

Brain Tumour Foundation of Canada, Support Staff- 1-800-265-5106 or 519-642-7755

Staff are available Monday to Friday, from 8:30am to 4:30pm to listen and offer support. Support calls are confidential, caring, and non-judgemental. You can also visit <http://www.braintumour.ca/621/care-and-support>

If you have any further questions about the research, you can contact:

Francesca Smithson Evans, *Trainee Clinical Psychologist*, at f.smithson-

evans@2013.hull.ac.uk

Or

Dr Emma Wolverson, *Clinical Psychologist*, at E.Wolverson@hull.ac.uk

Or

Dr Catherine Derbyshire, *Macmillan Consultant Clinical Neuropsychologist*,
at Catherine.Derbyshire@hey.nhs.uk

Thank You!

Appendix I: Thematic Analysis of Qualitative Responses

Thematic Analysis

Ninety-six participants (69.5%) responded to the open response box. Nine themes were developed in total, with four sub-themes forming within the theme of 'Experience of Professionals and Healthcare Systems'. These are summarized in narrative format below. Quotes are reported verbatim with coinciding participant numbers.

Getting the News: Sudden vs Prolonged

Participants described the speed at which they were diagnosed. It appears that those who wrote about this either had a very sudden onset and diagnosis, and in some cases this was a medical emergency, or they had a prolonged experience before receiving the correct diagnosis.

Sudden

"This tumor came out of nowhere for me and my family." (7)

"My meningioma was diagnosed following and ER visit two months ago. I was rushed into emergency surgery with 24 hours. I was admitted to the hospital less than 2 hours after my diagnosis." (19)

Prolonged

“I was not properly diagnosed for two years and was initially told I had a malignant brain tumor and had five years to live - oh, and I was eight months pregnant at the time and going to have an emergency section the next day! Obviously even though this diagnosis was later discarded (in favour of a blood clot, then MS, then a mystery lesion and then finally a low grade glioma) the next five years were pretty traumatic as I had lost faith in the medical profession.” (61)

“After repeated visits to doctors I had been repeatedly prescribed stronger painkillers, but had no diagnostics. My symptoms escalated to dizziness and nausea, until collapsed. I attended an ENT centre for tests, they quickly reconised it could be a brain tumor. I was subsequently transferred to the hospital for a CAT scan, which showed a shadow. The MRI was interpreted as a GBM2, operable and curable. In my confused state it was a relief, as I finally had a conclusion.” (16)

Making Sense Of The Symptoms And The Treatment Effects

Participants frequently reported the type of tumor they had and the treatment they had received, or may need in the future, as an apparent way of offering context to their experiences. Participants also wrote extensively about the symptoms they experienced, particularly about having very strange symptoms or no symptoms at all in the lead up to their diagnosis.

“I did not know I had a brain tumor. I never had headaches or any symptoms.”
(10)

"I was lactating out of one breast which lead to my diagnosis." (2)

Participants detailed the continuing impact of their brain tumor, and after-effects they experience from treatments, seemingly trying to make sense of these. This involved a huge range of experiences including headaches, epilepsy, weakness, weight gain, anxiety, poor concentration, and difficulties with memory, language, learning, and executive functioning. Additionally, participants were no longer able to drive, had to give up their hobbies, were forced to stop working and suffered financial implications. Above all, participants wrote about the huge effect that fatigue now has on their life and the way in which this limits them.

"I feel that it is the treatment that has had the biggest impact on my life rather than the tumor itself, as the radiotherapy and chemotherapy have meant I have had to have long periods where I have not been able to work, and that the drugs have had an effect on my ability to cope with certain situations in life." (44)

"I suffer extreme fatigue yet I only sleep for a few hours at night. I cannot tolerate noise or being in busy social situations. I have bad short term memory" (67)

Experience of Professionals and Healthcare Systems

Participants wrote about their experiences with professionals and healthcare systems during their brain tumor journey. It is apparent that participants had diverse experiences of this, and sub-themes formed.

Approach of Professionals

Professionals approaches towards participants and the disclosure of their diagnosis was written about throughout the data. Some participants described very positive experiences which included both socioemotional behaviors, such as kindness and compassion, and information aspects, for example, giving clear and honest information regarding their tumor.

“Without exception they have been kind, compassionate, clear, honest and I feel fortunate to be under their care” (49)

“The radiation oncologist was the first to say the word. I had to ask him to clarify what he was saying. I appreciated his direct approach when he stated matter of factly that I had a cancerous brain tumor. That day is something I will never forget.” (70)

Negative experiences of professionals’ approach also involved socioemotional behaviours, for example professionals being patronizing, dismissive, and insensitive. Regarding the information side, participants explained they felt uncomfortable asking questions or that information provided was rushed and there was no time for questions.

“He makes me feel uncomfortable about questioning him and is patronising and dismissive.” (42)

“The neurologist yelled at me for crying because she said it was a false tumor. As I was laying on a table after a lumbar puncture, she came in & told me I had either MS or a brain tumor & left the room.” (47)

The means of disclosure was also discussed and considered important. Some participants reported being told their diagnosis over the telephone, which was expressed as an inappropriate method of disclosure.

“I was then given my scan results/diagnosis over the phone. I was horrified as it gave me no time to prepare any questions & was a horrible way to be told. Took me a long time to get over this.” (66)

“I was told over the phone at 5:45 on a Friday. I also live alone so had no one to discuss it with and it was very unexpected for me.” (89)

Unacknowledged and Dismissed

There was a strong impression throughout the data that participants have felt unacknowledged and dismissed by professionals and the healthcare system throughout their journey with a brain tumor. This spans from their initial symptoms and symptom progression being dismissed or attributed to other causes, to a lack of follow-up support and on-going care post-diagnosis and treatment.

“I don't understand what is supposed to happen from here? My symptoms have progressed but he refuses to acknowledge them.” (42)

“the support after treatment drops off and you are left on your own more - the impact to everyday life is huge and everything is very difficult” (91)

Multiple Professionals Involved in Care

Throughout their brain tumor journey participants have a number of different professionals and specialties involved in their care. Participants wrote about their experiences of having multiple professional involvement and the disagreements, contrasting approaches, and lack of communication and coordination between them this came with.

“...if the appointment difficulties are not enough, I have at the moment 4 specialists who hardly agree on anything. There is my neurosurgeon with one opinion (which I share 100%) and my neuro-ophthalmologist, neuro-endocrinologist and neuro-radiologist. They do not share information. In every appointment I have to tell them what the others think.” (36)

“She [initial oncologist] was very clinical/medical in explaining my brain tumor and was not open to me asking questions, she was very curt and did not have a good 'bed-side' manner...I was assigned my permanent Oncologist shortly after and he is kind, patient, explains anything I ask and is very open to me asking questions. He also has a very good sense of humour” (34)

Being in Limbo Or Having No Place In The System

The intervals encountered between referrals and appointments, and tests or scans and the results left participants with the uncomfortable sense of being in 'limbo'. Additionally, participants conveyed the feeling of being lost in the medical system or having no place in it, either due to administration errors, their type of tumor, or phase of treatment.

"I found when I was told about tumor your then left in limbo for what seems ages till you see neurosurgeon." (23)

"I feel without a 'home' I don't have cancer, i don't technically have a tumor at the moment, yet I live with side effects and constant concern that it will come back" (11)

Information Deficiencies and Needs

The information received regarding their brain tumor from professionals was predominantly expressed as being lacking, unclear, sometimes incorrect, or concealed for a period of time. It was also apparent that the information that was lacking was often fundamental information about participants' diagnosis and illness progression.

"i hear people talk about 1 2 3 4 i dont know what that means" (29)

"I was satisfied, to begin with but last year, as my condition worsened, I discovered that my tumor had been steadily growing for 3 years. However, after each six-monthly scan I was told that all was fine and there was no progression... I felt, and still feel, let down, disappointed and confused as to why I wasn't kept in the picture." (39)

Moreover, it is apparent participants' desired additional information to that of what they received from professionals, and to fulfil this need participants turned to other sources, a prominent place being the internet.

"This I looked up on Wikipedia, only to find that this was a GBM 4 and ultimately terminal." (16)

"Facebook sites have been my saviour for both information and understanding." (3)

Powerful Feelings

A theme that emerged through the data was the expression of a number of powerful and difficult feelings. These feelings were articulated in a raw and honest way and gave a sense of how enduring these emotions can be for people living with a brain tumor. Just a few examples of these powerful feelings are devastation, "fear" (65), terror, trauma, shock (55, 77, 82), sadness, stress (6, 12, 16, 70, 85), guilt (70), inadequacy, resentment, anxiety (2, 11, 66, 76, 96), frustration (16, 69), anger (16), "dismissed" (74), and "unloved" (43).

"[to] be diagnosed with a glioblastoma is frankly terrifying, and at times totally overwhelming and sad." (49)

"I still feel angry, robbed & resentful 7 years down the line." (66)

Loved Ones

Participants' loved ones, their family, partners, and friends, were written about in the data both in terms of the positive support they offer throughout their illness, but also the more difficult situations that have arisen. Regarding support, participants described with a huge sense of gratitude how they relied on and received practical as well as emotional support from their loved ones. A smaller number of participants also wrote about the role their family took in helping them understand information provided by professionals, as well as filtering this information at a time when they believed it would have been difficult for them to hear.

"My daughter has arranged all appointments and helped with my care as I was paralysed down my left side... My husband has not left my side for 1 day in the last year. He steps in hospital with me and reassures me and helps care for when I'm at home. My son has kept the family business going." (14)

"I have the best support from my partner and friends. I don't know what I'd do without them." (44)

On the other hand, participants also described the negative consequences that having a brain tumor can have on their loved ones and their personal relationships. Their condition was written about as being a 'burden' on others, with it being difficult for them to understand, particularly for children. The effect of their tumor led to changes in the role participants had to take in their relationships, and in some cases it ultimately lead to relationship breakdowns and feeling socially isolated from others.

"...ultimately my condition took its toll on our relationship and he ended our engagement. I now worry about the effect my tumor will have on any future relationship, as it is a heavy burden for a partner to bear." (39)

"I struggle with the pressures this diagnosis has placed on my family. They are my rock and support me without waiver nevertheless I feel a guilt this burden places on my family. I place stress on my young children as they are in a situation they don't understand." (70)

Longing for, and Seeking Normality

The concept of 'normality' was referred to throughout the data. Participants expressed they wanted to get back to their normal life and to be able to do normal things once more.

"I just want to live the life I had before this bastard invaded our lives." (33)

"I have an 11 year old daughter who I'd love to be able to do more (normal) things with." (41)

Participants also conveyed continuing with their life normally after their diagnosis, often due to not knowing what else to do, or adjusting to a 'new normal'.

"I lived with the diagnosis for 3 months before my treatment, and carried on as normal, not knowing how else to be." (55)

"I try to live as normally as possible and not make excuses for my tumor or let it define who I am." (80)

Finding Strength, Fighting, and Taking Control

Participants wrote about the strength they have needed when facing their brain tumor and the challenges it brings, and what they have fought for. Participants wrote about this both in terms of them as individuals, but also in relation to their family; fighting the system to get the care they need as well as being strong and fighting for others.

“I have had to stay strong and fight through this.” (19)

“I am going to be strong and fight for sake of seeing and experiencing life with my family.” (10)

Additionally, there was a sense that participants attempt to gain some control over their condition through engaging in alternative approaches and altering their daily life to manage their symptoms. However, participants also expressed a lack of control they can feel regarding their condition, and this could be heightened when treatments have finished as they then don't have that input into their condition.

“Through changing my routine and activity I have managed to get the dizziness under control under normal circumstances - which has improved my quality of life considerably” (64)

“I am an avid reader and have recently read books on how our minds can heal our bodies, with biological proof, so for me this is what I've been working on to try and heal my brain tumor. For me to feel some kind of control over my cancer” (9)

Hope and Positivity

Participants wrote about the hopes they now have. They described particular hopes that included the hope that treatment can improve their condition and that a cure for brain tumors will be found; waiting to receive some hope from healthcare professionals and the hope that their diagnosis experience was a one off; and the hope that their symptoms will improve and they can regain some independence.

“I hope a cure will be found soon.” (10)

“[I] will hopefully regain some independence when I can.” (27)

Participants also wrote about the positive aspects of their lives. Participants wrote about choosing to concentrate on the good things in their life and what they are still able to do, as well as the positive things that have come from their experience with a brain tumor. Within this participants acknowledged that to get to a place of positivity, it was necessary for them to experience the negative.

“Things do get hard sometimes but if I concentrate on all the positive good stuff in my life it outweighs the bad.” (41)

“I've learnt to love the little things in life a lot more, things that I took for granted before like my children smiling and laughing or my wife catching me looking at her and then her smiling at me just mean so much more” (20)

Appendix J: Examples of Qualitative Data Analysis

Causal Representations Categorisation example

	Q23
<u>1</u>	I have no idea <u>Uncertain</u>
<u>2</u>	genetics <u>Physical- internal</u>
<u>3</u>	<u>Physical- internal</u> Genetics
<u>4</u>	<u>Physical- internal</u> genetics
<u>5</u>	<u>Physical- internal</u> Genetics
<u>6</u>	<u>Physical trauma</u> <u>Head injury</u> <u>skiing</u>
<u>7</u>	workplae <u>Environmental</u> e
<u>8</u>	s <u>Stress</u>
<u>9</u>	Bad luck
<u>10</u>	<u>Environmental</u> <u>Radiation</u> <u>Treatment</u>
<u>11</u>	Premature birth <u>Congenital</u>
<u>12</u>	My very stressful job <u>Stress</u>
<u>13</u>	Hormones (fertility drugs)
<u>14</u>	<u>Virus/h</u> <u>Hormones</u>
	<i>Participant discontinued</i>
<u>15</u>	<u>Physical- internal</u> Hereditary
<u>16</u>	<u>h</u> <u>Hormones</u> from pill
<u>17</u>	<u>Stress</u> from dealing with my parents (ill health, alcoholism)
<u>18</u>	I d <u>Uncertain</u> ont know
<u>19</u>	my sister died of non hodgkins lymphoma which I have but primary in the brain <u>Genetic- Physical- internal</u>
<u>20</u>	<u>Chemicles</u> <u>Environmental</u>

Bad luck

Fate, Chance, Karma, 'One of those things', random causes

Physical-internal

Genes/genetics, Hereditary, Congenital, NF1/2, Genetic mutation, Mutation, Hormones, immune problems

Stress

Anxiety, Depression, Grief

Uncertain

Don't know, Cause unknown, No cause or N/A

Physical trauma (physical- external)

Head injury, Accident, Fall, Etc.

Demographics

Environmental

Pesticides, Pollution, Radiation, Smoking parents, Wifi signals

Lifestyle

Smoking, Alcohol, Diet, Mobile phone use, Pressures of everyday life

Other

Appendix J: Example of Mediation Analysis

Testing for the mediation effect of illness perceptions on the relationship between Information Combined and Total QoL.

Y = Total QoL

X = Information Combinad

M1 = Cognitive Representations

M2 = Emotional Representations

M3 = Illness Comprehensibility

Outcome: Cognitive Representations

Model Summary

R	R-sq	MSE	F	df1	df2	p
.1123	.0126	55.8148	1.7380	1.0000	136.0000	.1896

Model

	coeff	se	t	p	LLCI	ULCI
constant	29.9835	1.7790	16.8540	.0000	26.4654	33.5017
InfoComb	.0289	.0219	1.3183	.1896	-.0144	.0722

Outcome: Emotional Representations

Model Summary

R	R-sq	MSE	F	df1	df2	p
.0255	.0007	21.5218	.0886	1.0000	136.0000	.7664

Model

	coeff	se	t	p	LLCI	ULCI
constant	15.9158	1.1047	14.4074	.0000	13.7312	18.1004
InfoComb	-.0040	.0136	-.2977	.7664	-.0309	.0228

Outcome: Illness Comprehensibility

Model Summary

R	R-sq	MSE	F	df1	df2	p
.2298	.0528	7.8808	7.5818	1.0000	136.0000	.0067

Model

	coeff	se	t	p	LLCI	ULCI
constant	6.0056	.6685	8.9839	.0000	4.6836	7.3276
InfoComb	.0227	.0082	2.7535	.0067	.0064	.0389

Outcome: Total QoL

Model Summary

R	R-sq	MSE	F	df1	df2	p
.6011	.3613	508.5540	18.8062	4.0000	133.0000	.0000

Model

	coeff	se	t	p	LLCI	ULCI
constant	159.2646	10.3812	15.3416	.0000	138.7309	179.7982
CogRep	-.9803	.2938	-3.3360	.0011	-1.5615	-.3991
EmoRepIP	-2.5624	.4652	-5.5081	.0000	-3.4826	-1.6422
IllnessComp	1.4556	.7054	2.0633	.0410	.0602	2.8509
InfoComb	.1231	.0683	1.8020	.0738	-.0120	.2581

Direct And Indirect Effects

Direct effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.1231	.0683	1.8020	.0738	-.0120	.2581

Indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
TOTAL	.0150	.0497	-.0820	.1139
CogRep	-.0283	.0248	-.0909	.0121
EmoRepIP	.0104	.0339	-.0612	.0752
IllnessComp	.0330	.0204	.0032	.0848

Testing for the mediation effect of illness perceptions on the relationship between Information Combined and Social/Family Wellbeing

Y = Social/Family Wellbeing

X = Information Combinad

M1 = Cognitive Representations

M2 = Emotional Representations

M3 = Illness Comprehensibility

Outcome: Cognitive Representations

Model Summary

R	R-sq	MSE	F	df1	df2	p
.1123	.0126	55.8148	1.7380	1.0000	136.0000	.1896

Model

	coeff	se	t	p	LLCI	ULCI
constant	29.9835	1.7790	16.8540	.0000	26.4654	33.5017
InfoComb	.0289	.0219	1.3183	.1896	-.0144	.0722

Outcome: Emotional Representations

Model Summary

R	R-sq	MSE	F	df1	df2	p
.0255	.0007	21.5218	.0886	1.0000	136.0000	.7664

Model

	coeff	se	t	p	LLCI	ULCI
constant	15.9158	1.1047	14.4074	.0000	13.7312	18.1004
InfoComb	-.0040	.0136	-.2977	.7664	-.0309	.0228

Outcome: Illness Comprehensibility

Model Summary

R	R-sq	MSE	F	df1	df2	p
.2298	.0528	7.8808	7.5818	1.0000	136.0000	.0067

Model

	coeff	se	t	p	LLCI	ULCI
constant	6.0056	.6685	8.9839	.0000	4.6836	7.3276
InfoComb	.0227	.0082	2.7535	.0067	.0064	.0389

Outcome: Social/Family Wellbeing

Model Summary

R	R-sq	MSE	F	df1	df2	p
.3388	.1148	37.5985	4.3120	4.0000	133.0000	.0026

Model

	coeff	se	t	p	LLCI	ULCI
constant	14.0141	2.8227	4.9648	.0000	8.4309	19.5973
CogRep	.0360	.0799	.4504	.6532	-.1221	.1940
EmoRep	-.2256	.1265	-1.7839	.0767	-.4758	.0245
IllnessComp	.4012	.1918	2.0915	.0384	.0218	.7806
InfoComb	.0453	.0186	2.4410	.0160	.0086	.0821

Direct And Indirect Effects

Direct effect of X on Y

Effect	SE	t	p	LLCI	ULCI
.0453	.0186	2.4410	.0160	.0086	.0821

Indirect effect of X on Y

	Effect	Boot SE	BootLLCI	BootULCI
TOTAL	.0110	.0076	-.0002	.0313
CogRep	.0010	.0029	-.0024	.0114
EmoRepIP	.0009	.0036	-.0053	.0102
IllnessComp	.0091	.0062	.0013	.0301

Thematic Analysis- Coding example

36	<p>I had a negative reaction to gamma knife treatment. This resulted in brain edema which necessitated the use of steroids. <u>The tumour is still there and in a highly sensitive location where a biopsy is not available.</u> I have <u>experienced all the side effects</u> associated with the Dex that I was taking.</p>	<p><i>Side/after-effects of treatment</i> <i>Uncertainty- no biopsy</i></p>
37	<p><u>Im still doing a lot of physical activities</u> swimming dancing some outdoor activities i will never 100 percent what i was but i can live with it sometimes its frustrating but i keep positive and keep on going <u>good family support</u></p>	<p><i>Frustration</i> <i>Positivity and what they still can do</i> <i>Family +</i></p>
38	<p><u>I am not now satisfied with my original neurosurgeon.</u> I was satisfied, to begin with but last year, as my condition worsened, <u>I discovered that my tumour had been steadily growing for 3 years.</u> However, after each six-monthly scan I was <u>told that all was fine and there was no progression.</u> When I started to have severe seizures last year, I was finally able to compare my MRI scan at diagnosis, with the then current one. There was a big difference. <u>I felt, and still feel, let down, disappointed and confused as to why I wasn't kept in the picture.</u> I had also been told by this neurosurgeon that my tumour was inoperable due to its deep position. I didn't discover until last year, when I met a new (my current) neurosurgeon, that what he actually meant was that HE was unable to operate. My new surgeon, one year ago, was able to re-sect 90% of my tumour and <u>my diagnosis, and prognosis has changed.</u> <u>My partner and I were deeply shocked the day we found out that not only had the tumour been growing all along, but that I would now undergo brain surgery.</u> We also <u>felt misinformed following my surgery, that my recovery would be within a few months.</u> Personally I feel I did make a quick recovery, but <u>my partner remembers me being frustrated and depressed about not moving on quickly enough, and ultimately my condition took its toll on our relationship and he ended our engagement.</u> <u>I now worry about the effect my tumour will have on any future relationship, as it is a heavy burden for a partner to bear.</u></p> <p>On a day to day basis I don't think about my tumour much, <u>I just concentrate with getting on with life.</u> However, the biggest and most debilitating side effect is the fatigue which is almost unbearable at times and leaves me needing to sleep during the day.</p>	<p><i>Concealing information</i> <i>Dissatisfaction, disappointment, confusion</i> <i>Misinformed</i> <i>Frustration</i> <i>Treatment and recovery (speed)</i> <i>Impact on relationships- past and future. Burden</i> <i>'getting on with life'</i> <i>Side effects</i></p>
53	<p><u>Although my tumour is considered benign I have found the diagnosis , surgery and follow up extremely difficult to cope with.</u> I have had <u>little emotional</u></p>	<p><i>Diagnosis, treatment, and</i></p>

<p><u>support professionally and was made so uncomfortable at a local support group that I left it. My main support comes from friends and the online meningioma community</u></p>	<p><i>follow-up</i></p> <p><i>Lack of emotional support from professionals</i></p> <p><i>Uncomfortable at support group</i></p> <p><i>Friend support + Technology/social media support</i></p>
<p>54 <u>It was a very big shock for me, but I played it down significantly which may have been to my detriment. I lived with the diagnosis for 3 months before my treatment, and carried on as normal, not knowing how else to be. Upon having treatment, and feeling surprisingly good, I was lulled into "everything will be back to normal now" and that isn't the case. The emotion of it all has been delayed because of my coping mechanism prior to treatment, and I feel broken.</u></p>	<p><i>Shock</i></p> <p><i>Downplaying- by person</i></p> <p><i>In limbo before treatment?</i></p> <p><i>Continue as 'normal' & lulled into 'normal'</i></p> <p><i>Feeling 'broken'</i></p>
<p>55 <u>I have resigned as an assistant headteacher and down scaled as my life expectancy is reduced and the ever growing tumour will require another operation when its starts to cause me major problems, one being balance, coordination and hydrocephalus.</u></p> <p><u>With this in mind you have to remain positive and continue to try your upmost in everything you do.</u></p> <p><u>I try to keep myself busy all the time to distract me from my fears</u></p>	<p><i>Loss of job</i></p> <p><i>Tumour growth</i></p> <p><i>Positivity</i></p> <p><i>Busy- distract from fears</i></p>

Appendix K: Reflective Statement

As I look back to the start point of this research rollercoaster, the fourth year research fair, there was only ever one topic for me. I knew I wanted to do my thesis in a neuropsychology related area, as this is the main interest of mine and I was under no illusion it wasn't going to be tough, and I needed something I could remain interested in for three years. I remember excitedly telling my parents and my Granny Pat that I may be able to do my research in brain tumours. My Granny Pat was a Nurse whose favourite job was assisting in brain surgery, maybe it's a genetic interest?

During the design of the research I was worried about biting off more than I could chew, which was a territory I strayed into with my undergraduate research. Perhaps I also risked this with the qualitative response box in my empirical paper, I did not expect the amount of people to respond to this as they did. However, when I was analysing the data the reason for this became clear; of course people would want to tell their story about something which has impacted their lives so immensely. I am very pleased that I included this element of the research, as it not only provided supporting evidence for my quantitative results; it allowed me to begin to develop a new skill and broaden my interests.

The decision to take this research internationally cannot be credited to me. This was my research supervisor, Catherine's suggestion, and at the time, for me it was a very scary suggestion; how would I ever manage that!? Eventually though, this became one of my most relished aspects of this research; it almost became a competition with myself to see how far I could spread my research.

Conducting research online and using social media to promote this is something I would recommend to any potential researchers whose study would be appropriate for this. Not only did it allow me to personally manage the research advertisement to some extent, but it allowed me to connect with people I never would have had the chance to otherwise. I also feel it is important to keep up with the times regarding technology, and use this to our advantage for research.

I have been struck by the passion of not only the people living with a brain tumour who participated in the study, but also the broader network of people who are connected to them. I was contacted by a number of people who have lost a loved one due to a brain tumour who wanted to take part in the research on their behalf, or help in any way they could. I found it very difficult to tell them that unfortunately they could not complete the research.

Possibly quite uniquely, I have found research a place of solace at times when other aspects of the course have been overwhelming or downright frustrating. Research has made sense to me, it seems to fit the way I tend to think. This was especially true when it came to the systematic literature review, which during the data collection phase I found very containing. This isn't to say I haven't struggled though. I remember finding the ethics application particularly difficult, but looking back on this now, I can't recall quite why. Therefore, when when I received the approval letter with no corrections and the request to use my application as a good example, shock was an understatement. I was thrilled but also concerned at the time that they had sent this to the wrong person. That is another internal struggle I have faced during this process: 'imposter syndrome'. The anxiety that I am not really 'good enough' to be doing this, and the fear that I will be disappointing my supervisors.

The writing up process evoked mixed feelings in me. On the one hand it allowed me to cement my understanding of my data and only increased my interest for it. On the other hand, it took significantly longer than I had expected. It has most certainly been a journey and not an event.