THE UNIVERSITY OF HULL

Exploring patient-neurosurgical team inter-relationships throughout the perioperative period of awake craniotomy

being a Thesis submitted in partial fulfilment of the requirements for the

Degree of Doctor of Clinical Psychology in

The University of Hull

by

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June 2015

Total Word Count (excluding references and appendices): 43,723

Dedications

This thesis is dedicated firstly to I AM who has been an unchanging Presence throughout my writing.

I also dedicate this thesis to my parents, Margaret Ruth Dearden and Norman Mark

Dearden, whom I love and honour greatly.

Acknowledgments

My deepest gratitude goes to the people who gave up their time to discuss their experiences of awake craniotomy. Without their honesty and openness, this piece of research would not have been possible. It was truly a privilege to hear their stories.

My thanks also goes to Mr Shailendra Achawal, Mr John Goodden, Suzanne Spink, and Dr Catherine Derbyshire who gave their time and effort to make participant recruitment possible.

My upmost thanks also goes to my research supervisors, Dr Emma Wolverson and Dr Catherine Derbyshire. What an insightful journey it has been! Thank you for supporting and compelling me to carry on.

My thanks also goes to the legend that is Dr Tim Alexander, and the dancing enthusiast, Dr Lesley Glover, for answering many questions along the way. Your knowledge is boundless!

Great appreciation also goes to Dr Peter Oakes. Your kind, honest and 'trustful' words will remain with me always. Thank you and Shalom.

Thank you to all my fellow trainees who have made the previous four years a valuable experience. I have never laughed so much: "*put some more coal in it!* (**cue sound effects*)"

To my wonderful, selfless and patient family, thank you for your unconditional love and support. I would not have been able to complete this without you.

My thanks also goes to my church family who have prayed for me throughout this journey. You have been a great source of encouragement!

A special thanks goes to Chris, Richard and Pedro for being life-long friends and providing endless entertainment throughout this process. Your random visits to Hull, fishing lake trips and Mario star coins proved invaluable!

Eternal gratitude also goes to my friends on Facebook who were willing to retrieve many journal articles for me when I struggled to gain access.

To my darling Sophie, words simply cannot express how grateful I am. What a wonderful, kind, patient, and resilient girlfriend! You have been an endless and unfailing source of genuine encouragement and support over the past four years and have taught me the meaning of 'patient endurance'. Thank you for helping me to persevere and for persevering yourself through my venting (my apologies)! You have shown me His Heart throughout.

Most of all, my Highest Praise goes to God, His son Jesus Christ, and the Holy Ghost, who have faithfully fulfilled their promise to complete the good work they began in me.

Overview

The portfolio thesis is divided into three parts: a systematic literature review, an empirical study, and appendices.

Part one is a systematic literature review exploring definitions, measures and influencers of health-related quality of life (HRQofL) in brain tumour (BT) populations. The review was undertaken as no BT-specific HRQofL definition currently exists, literature remains unclear regarding the existence of reliable and valid BT-specific measures, and little is known about factors associated with HRQofL that may be amenable to change. A systematic search of four databases identified 13 relevant studies. No accepted HRQofL definition emerged. Only two validated BT-specific HRQofL measures were reported and numerous variables influencing HRQofL were identified within themes of 'patient', 'tumour', and 'social support' factors. Findings provided recommendations for future research and useful insights for refining clinical practice.

Part two is an empirical study exploring how both patients and neurosurgical team members experience awake craniotomy (AC) and make sense of their perioperative interactions. The qualitative study aimed to enhance knowledge surrounding efficacious approaches to build positive patient-practitioner relationships with the potential to improve overall AC experience. A patient and neurosurgical team group, each comprising eight participants, were interviewed and the data was analysed using Interpretative Phenomenological Analysis (IPA). Four superordinate and six subordinate themes, and three superordinate and seven subordinate themes emerged within patient and neurosurgical team groups respectively. Themes are discussed within the context of wider healthcare literature, identifying relevant clinical implications.

Part three consists of appendices supporting the systematic literature review and the empirical study. It also includes a reflective statement of the 'research experience'.

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Part One

Systematic Literature Review

Definitions, measures and influencers of health-related quality of life in brain tumour populations: a systematic review

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This paper is written in the format ready for submission to Brain Impairment. Please see Appendix A for the guidelines for contributors.

Word Count (Excluding References): 15,810

Abstract

The health-related quality of life (HRQofL) of patients diagnosed with a brain tumour (BT) is an important priority for health-care professionals given improving survival rates combined with illness-related morbidities and psychosocial consequences. No consensus currently exists when defining HRQofL for BT populations and the literature remains unclear regarding the existence of reliable and valid BT-specific measures. Furthermore, little is known about factors associated with HRQofL that may be amenable to change. The present study aimed to scrutinise published literature that utilised validated and reliable questionnaires to ascertain: how HRQofL is defined, what BT-specific measures exist, and what factors influence HRQofL in BT populations. A systematic review of four databases (MEDLINE, Academic Search Premier, CINAHL Plus with Full Text and PsycINFO) was conducted in May 2015. Thirteen studies were identified following application of inclusion and exclusion criteria. A narrative synthesis approach was undertaken that included a quality appraisal of articles. Numerous variables influencing HRQofL were identified within themes of 'patient', 'tumour' and 'social support', although no association with 'treatment' factors emerged. Results provide recommendations for future research and contribute useful insights for refining clinical practice.

Key Words: brain tumour, health-related quality of life, systematic literature review

Introduction

Primary brain tumours (BT) remain a significant source of morbidity and mortality. They occur due to abnormal and uncontrolled cell division within the central nervous system (CNS), cranial nerves, meninges, skull, pituitary and pineal glands (NHS England, 2013). BTs are graded I-IV by the World Health Organisation (WHO) based on cell/tissue type, location and degree of malignancy (Louis, Scheithauer, Budka, von Deimling, & Kepes, 2000). Low-grade (I-II) tumours are characteristically slow growing with relatively distinct boundaries (Kalkanis, Quinones-Hinojosa, Buzney, Ribaudo, & Black, 2000). High-grade (III-IV) tumours are malignant and defined by rapid growth rates, infiltration to nearby brain tissue and higher risk of recurrence following treatment (Ownsworth, Hawkes, Chambers Walker, & Shum, 2010).

In 2010, 9156 new BT patients were registered in the United Kingdom (UK), with approximately 14.8 cases for every 100,000 males and 14.6 for every 100,000 females (Office of National Statistics, 2013). BTs accounted for 4975 deaths in 2011 being the 8th most common cause of cancer mortality in the UK (Office for National Statistics, 2013). According to the Department of Health (DoH), cancer and tumour healthcare remains the third largest spending category, costing approximately £5.8 billion in 2011, which is increasing annually (Harker, 2012).

Treatments for BT include surgery (biopsy, debulking or resection), radiotherapy, chemotherapy and concomitant medications, either combined or in isolation (Chaichana, Halthore, & Parker, 2011). Advances in tumour molecular biology have augmented exploration and refinement of therapeutic avenues (Norden, Wen & Kesari, 2005). Treatment enhancements may improve survival but have associated impairments across all health domains (Neil-Dwyer, Lang, & Davis, 2000), which may be delayed in onset and of variable duration (Weitzner & Meyers, 1997). Furthermore, rapid interventions may limit time for patients to contemplate their diagnosis and treatment options (Salander, Bergenheim, & Henriksson, 2000). Despite modern treatment advances, long-term survival outcomes for patients with high-grade BTs remain poor, with diffuse low-grade tumours transforming to high-grade in a median duration of five to seven years (van den Bent et al., 2005).

BT morbidity is influenced by treatment related effects and a range of interrelating biopsychosocial factors which may persist for the rest of patients' lives (Hamam-Raz, Solomon, Schacter, & Aziz, 2007). Frequently reported general symptoms include headache, nausea, vomiting, insomnia, seizures and fatigue (Goebel, Stark, Kaup, von Harscher, & Mehdorn, 2011). Patients also experience disturbances secondary to focal neurologic deterioration or treatment, such as motor and sensory deficits, aphasia and personality changes (Heimans & Taphoorn, 2002). Furthermore, cognitive difficulties are described that comprise attentional, memory and executive impairments in verbal and non-verbal domains (Hahn et al., 2003). To date the majority of research has focused on aspects of these functional and cognitive impairments (Dijkstra et al., 2009) and, in contrast to the wider cancer literature, paid little attention to associated psychological and social disturbances (Arnold et al., 2008).

Experiencing a life-altering and potentially life limiting diagnosis, uncertainty regarding the future and functional impairment resultant from the tumour and treatment will undoubtedly affect patients' psychological health (Giovagnoli, 1999). Predictably, prevalence rates for clinical depression and anxiety are as high as 62.5% in adults treated for low and high grade BTs (Arnold et al., 2008). Moreover, Zabora, Brintzenhofeszoc, Curbow, Hooker and Piantadosi (2001) studying fourteen cancer diagnoses reported patients with BTs to have the second highest levels of psychological distress after lung cancer. This highlights the potential contribution of psychological

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components and personal appraisals in adjustment to a BT diagnosis. Within wider cancer populations, patients' subjective views concerning their illness and manageability of the situation are established as predictive of emotional distress (Jenkins & Paragment, 1998). Moreover, research exists surrounding BT patients' perception of social support. Brooker, Burney, Fletcher, and Dally (2009) suggest that patients' psychosocial experiences included social isolation, inability to engage in previously enjoyed activities and undesired retirement from employment.

The combination of increased survivorship for people living with BT and treatment related biopsychosocial morbidities highlights patients' health-related quality of life (HRQofL) as an increasingly relevant area of clinical neuro-oncology for research (Hottinger, Yoon, DeAngelis, & Abrey, 2009). HRQofL has its foundations in the WHO definition of health: "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHOQOL Group, 1995). Multiple classifications of HRQofL have been proposed for BT populations (Brooker et al., 2009), with widespread agreement that HRQofL is multi-factorial and may incorporate an individuals' perception of illness impact on physical, psychological and social well-being (Bowling, 2005). Capturing the dynamic interplay between the numerous biopsychosocial and treatment factors unique to BT patients is also essential to any HRQofL definition.

Until recently, there has been limited data surrounding HRQofL for BT patients in routine practice (Jalali & Dutta, 2012) with most evaluations arising as secondary endpoints from clinical trials (Budrukkar et al., 2009). This is concerning as the wellinformed consenting patients of clinical trials may score differently to patients in clinical practice (Budrukkar et al., 2009). Fortunately, HRQofL is now being incorporated more often as a primary endpoint in routine practice studies alongside traditional evaluations such as survival and physician evaluated toxicity (Osoba, Brada, Yung, & Prados, 2000). Hopefully this will lead to improved understanding of how to incorporate use of such tools into healthcare settings.

There is considerable diversity in measures employed to assess HRQofL within BT populations. Early studies evaluated solely observable functional domains of HRQofL (Karnofsky, Abelmann, Craver, & Burchenal, 1948). However, ratings correlated poorly with subsequent generic HRQofL measures, being insensitive to minor score changes and values remained high until patient death (Carson, Grossman, Fisher, & Shaw, 2007). Moreover, reliability and validity were observer dependent resulting in discrepancies between individual, relative and medical staff ratings, the latter groups underestimating difficulties (Ownsworth et al., 2010). More recent literature has employed a variety of tools designed to assess multidimensional aspects of HRQofL. However, these have been developed for general clinical populations or specific-cancer groups and accordingly their reliability, validity and applicability for BT patients remains unclear.

Regardless of assessment method, HRQofL serves as a strong independent predictor of survival for BT patients (Tsay, Chang, Yates, Lin, & Liang, 2012). Therefore, understanding the factors associated with HRQofL is an important priority for health care professionals (Pelletier, Verhoef, Khatri, & Hagen, 2002). Knowledge may inform the development of effective interventions, particularly for features amenable to change. Awareness of these factors could also ensure optimal care is maintained post-treatment. This is paramount as clinical guidelines are limited surrounding symptom management and interventions for psychological and cognitive problems within BT populations (Kangas, Williams, & Smee, 2012b). Additionally, understanding factors that influence HRQofL may modify therapy decisions by allowing consideration of their relative impact on HRQofL alongside longevity (Jakola et al., 2012). Moreover, examination of a heterogeneous BT patient sample could allow determination of similarities and differences in HRQofL associations across the disease spectrum.

A previous systematic literature review investigated factors influencing HRQofL in BT patients (Ownsworth, Hawkes, Steginga, Walker, & Shum, 2009). Studies examined were published between 1980 to January 2007. The review included a heterogeneous sample of low and high grade BT patients, with differing times since diagnosis and varying types of treatment. Consistent findings concerned associations between depression, performance status and fatigue and HRQofL. Particularly, measures of depression predicted HRQofL at time of diagnosis, post-treatment and long-term follow-up. However, relationships among pre-illness and brain tumour characteristics, psychosocial variables and HRQofL were unclear. An important review limitation was the diverse approaches to HRQofL measurement (general, cancerspecific, and BT-specific) which likely contributed to inconsistent results reported throughout. Additionally, HRQofL was not defined and it was unclear whether included studies had offered descriptions. Therefore, there is possibility that the parameters analysed did not truly reflect HRQofL in BT populations. Consequently, conclusions drawn may be limited.

In order to address the aforementioned limitations, this systematic review aimed to apply a consistent approach examining only published literature that utilised valid and reliable measurements to investigate factors influencing HRQofL in BT populations. The following research questions were identified:

- 1. How is HRQofL defined within BT literature?
- 2. What quantitative measurement tools exist to reliably and validly assess HRQofL in BT populations?
- 3. What are the factors influencing HRQofL in BT patients?

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Method

Literature Search Strategy

A systematic review of published literature was conducted in May 2015. The following four online databases were searched for relevant literature through the EBSCO service:

- MEDLINE provides access to over 5400 journals examining medicine, nursing, dentistry, veterinary medicine, health care and pre-clinical sciences.
- Academic Search Premier provided aces to over 4600 journals in key areas of academic study.
- CINAHL Plus with Full Text provides access to over 770 nursing and allied health journals.
- PsycINFO provides access to over 3000000 behavioural science and mental health citations.

Databases were selected following review of HRQofL literature in other health populations (Johansson, Dahlström, & Broström, 2006; Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013). Chosen databases also enabled a comprehensive search of medical, psychological and sociological factors.

Search terms are displayed in Table 1. and were selected based on research questions, through initial checks of key studies to ascertain significant words, assessment of HRQofL literature in other health populations (Johansson et al., 2006; Beerens et al., 2013), and through examination of systematic literature reviews involving BT populations (Moore et al., 2012; Sterckx et al., 2013). **Table 1.** Search terms for the systematic literature review.

Search Field	Search Terms	Rationale
Abstract	"quality of life" OR "QofL" OR	Search terms aimed to cover
	"QOL" OR "health#related quality	phrases pertaining to HRQofL
	of life" OR "HRQofL" OR	
	"HRQOL" OR well#being OR	
	"psycho#social function*" OR	
	"functional status" (AND)	
Abstract	"brain tumo*" OR "brain cancer"	Search terms aimed to capture
	OR "brain neoplasm*" OR "brain	the range of BT types
	disease" OR glioma OR blastoma	
	OR astrocytoma OR ependymoma	
	OR neuroma OR neurocytoma OR	
	meningioma (AND)	
Abstract	determinant* OR factor* OR	Search terms aimed to define
	correlate* OR predict* OR relate*	items relating to influential
	OR associate* OR emotion* OR	factors
	distress* OR depress* OR mood*	
	OR anxi* OR trauma* OR fatigue	
	OR support OR psycho* OR	
	psychia*	

Literature search results were limited using the following parameters to promote identification of relevant articles:

- Papers published in peer-reviewed journals to enhance scientific rigour.
- Search terms limited to paper abstracts to optimise inclusion of literature concerned specifically with factors influencing HRQofL in BT populations.
- Papers written in English due to limited resources available for retrieval and interpretation of reports written in other languages.

Geographical and temporal limitations were not employed to widen the search thereby optimising inclusion. Relevance and quality were further enhanced by applying inclusion and exclusion criteria. References from selected articles were hand searched to ensure any additional relevant studies were included. A prominent researcher in the field was also contacted to ascertain whether further articles could be incorporated¹.

Inclusion and Exclusion Criteria

The initial search strategy produced a total of 2487 results. These were reduced to 1164 after limiters were applied. Thereafter, duplicates (n=372) were removed leaving 792 articles. The titles and abstracts were screened and subsequent inclusion and exclusion criteria were applied:

¹ Associate Professor Tamara Ownsworth, School of Psychology and Applied Cognitive Neuroscience Research Centre, Griffith University, Brisbane, Australia.

Inclusion Criteria

- Participants are ≥18 years of age and have received a BT diagnosis during adulthood. This inclusion criterion was employed as evidence suggests brain tumours in adults differ significantly from paediatric brain tumours regarding incidence, tumour type and required treatment (Merchant, Pollack, & Loeffler, 2010).
- ii. Participants are at any illness stage. There is a paucity of evidence to develop a rationale for studying particular patient sub-groups based on time since diagnosis. Authors were unable to identify theoretical models examining how patients with BT adjust to their diagnosis and whether distinct illness stages occur. Perhaps individualistic responses surrounding experiences of having a BT are of greater importance. Therefore, this broad criterion was employed to maximise study inclusion.
- iii. Studies utilised a quantitative or qualitative design. This inclusion criterion was applied to ensure a variety of methods were utilised in capturing patient perceptions of HRQofL and influential factors.
 Information obtained through rich qualitative data was considered particularly valuable given the paucity of research in BT populations.
- iv. The main study focus is on factors influencing HRQofL in BT populations. Most HRQofL evaluations are conducted as a secondary end-point in clinical trials (Osoba et al., 2000). Consequently, this inclusion criterion appeared crucial to ensure articles most relevant to research questions were included.

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- v. It is an investigation that collects original (primary) data from patients (i.e., a primary study).
- vi. For quantitative studies only:
 - a. Acknowledges HRQofL as a multidimensional construct by investigating at least two domains. This inclusion criterion was applied as known individual constructs (e.g., functional status) have correlated poorly with overall scores of multidimensional HRQofL measurements (Mackworth, Fobair, & Prados, 1992). Currently, little is known regarding the singular aspects of HRQofL in brain tumour populations and how they are influenced. Therefore, the purpose of the review was to investigate the multidimensional nature of HRQofL, allowing examination at global and individual domains.
 - b. Utilises a HRQofL measure which is validated in primary brain tumour populations. There is considerable diversity in measures employed to assess HRQofL. Many tools are developed for general clinical populations in which validity is uncertain for BT patients. A previous review reported that different measurements likely contributed to inconsistent findings (Ownsworth et al., 2009). Therefore, this inclusion criterion was applied to ensure HRQofL was reliably assessed.

Exclusion Criteria

- i. Studies that do not specifically examine factors influencing HRQofL.
- ii. Participants below the age of 18 years.

- iii. Papers which are a case study, dissertation or literature review.
- iv. Papers focused on the development and validation of HRQofL questionnaires. These articles did not examine factors influencing HRQofL in BT populations and were rejected.
- v. Papers focused on biochemistry or cell biology.
- vi. Papers focused on caregivers' HRQofL.
- vii. Clinical trials documenting HRQofL outcomes following specific medical treatment protocol. These papers focused predominantly on survival outcomes, usually employing generic HRQofL questionnaires as secondary outcome measures.
- viii. Studies using a secondary analysis.
- ix. Studies where the patients' HRQofL is rated by another person. This criterion was applied as discrepancies are reported between individual and relative/medial staff ratings, with the latter group underestimating difficulties (Ownsworth et al., 2010).

Titles (n=792) were screened and assessed using the inclusion and exclusion criteria with non-compliant papers being rejected (n=689). Abstracts of remaining papers (n=103) were further assessed according to the aforementioned criteria. A total of 60 papers were rejected. The full text and references of remaining articles (n=43) were reviewed for inclusion and exclusion criteria. A total of 13 papers met all of the requirements. Studies were rejected from the review if the HRQofL measurement utilised was not validated in brain tumour populations (n=22), the study did not specifically examine factors influencing HRQofL (n=3), the focus was on the development and validation of a HRQofL questionnaire (n=2), the study was a clinical trial (n=1), participants below the age of 18 were included (n=1) or the paper was a

review article (n=1) (see Appendix B for references of full text articles rejected). No further studies were obtained through hand searching of references or contacting a prominent researcher. A summary of the article selection process is displayed in Figure 1.



Figure 1. A flowchart illustrating the article section process.

Quality Assessment

The quality of each included study was assessed using an adapted quality assessment tool (Appendix C). This allowed particular sensitivity to participant characteristics and study design as these qualities may determine the representativeness of findings and strength of conclusions. Heterogeneity of study methods and designs meant a single published quality measure was unsuitable to evaluate and compare quality. Consequently, five published quality measures were amalgamated and adapted to reflect the diverse methodology employed. The Mixed Methods Appraisal Tool, version 2011, (MMAT; Pluye et al., 2011) describes the methodological quality of qualitative, quantitative and mixed study designs. A second quality measure by Vandenbroucke et al. (2007) was developed for the assessment of three main observational study designs: cohort, case-control and cross-sectional studies. A third quality measure by Harden et al. (2004) assess non-experimental and qualitative research focused on people's perspectives and experiences. A fourth quality checklist by Downs and Black (1998) was originally developed to assess healthcare intervention studies. Nevertheless, specific questions were utilised to further evaluate results sections of quantitative research not covered by other checklists. A final quality measure by Spencer, Ritchie, Lewis, and Dixon (2003) was developed for appraising qualitative research, focusing on links between data, interpretation and conclusions. Specific questions were taken to further evaluate results sections of qualitative studies not captured by other checklists.

The adapted quality checklist was further modified in two ways. Firstly, five additional questions created by the authors were added to assess study quality not considered by other checklists. For example, "Has it provided an explanation or definition of quality of life in the literature review?" Secondly, the wording of two items were modified to better reflect the focus of review questions. For example, "Are the main findings of the study clearly described?" was modified to "Are the main findings relating to factors which influence HRQofL clearly described?"

The adapted quality checklist created from these measures was felt to allow sufficient evaluation of included studies. Nevertheless, it was recognised that the reported reliability of checklists differed and modifications may have affected reliability.

Sections 1, 2, 3 and 5 of the adapted checklist were applicable for all studies whereas section 4 was adapted according to the design and methodology of each study. Percentage scores were calculated with the highest possible rating being 100% and lowest achievable rating being 0%. The quality score obtained by a study did not affect its inclusion or exclusion. All study ratings ranged between 48% to 77% (see Appendix D for quality scores). A total of six studies; two with the highest quality score, two with middle ranging quality scores and two with the lowest quality scores were blindly rated by a researcher independent of the study. Cohen's Kappa indicated that inter-rater reliability was .58 (p<.001). This was considered a 'moderate agreement' according to Landis and Koch (1997). Discrepancies were discussed until a consensus was reached.

Data Analysis

Narrative synthesis was selected to summarise and explain the review's findings because of heterogeneity between studies. Sources of diversity included: study design, the use of different statistical analyses and the inclusion of participants at different illness stages. Integration of quantitative and qualitative is facilitated by this methodology, enabling findings from multiple sources to be reviewed (Dixon-Woods et al., 2006). Policy development and healthcare issues are informed greatly by a breadth of evidence employing various methodologies which allows enhanced understanding of topics (Harden et al., 2004).

The iterative process involved in conducting the narrative synthesis was informed by published guidance (Popay et al., 2006) and incorporated several elements:

- i. The development of 'change theories' to ascertain any mechanisms by which findings might be understood and interpreted.
- A 'preliminary synthesis' of the primary findings to collate key themes across included studies, describing direction and size of effects.
- An 'exploration of relationships' between study results and core aspects of populations, influential factors and contexts, to ascertain possible differences across articles.
- An 'exploration of robustness' to assess the strength of evidence when drawing conclusions and determining generalisability.

Data Extraction

A data extraction tool was developed to obtain relevant information from each included study thereby allowing the collation of information for a narrative synthesis (Appendix E). The article's author(s), aims, participant characteristics, methodology and measures, main results, conclusions, implications and quality score were recorded.

Results

Characteristics of included studies

Table 2. summarises methodological details, key findings and quality ratings for the 13 included studies. The sample sizes of included studies ranged from 21-257 altogether totalling 1041 BT participants. Of the 13 studies, 11 reported details regarding gender. The proportion of males and females in these studies ranged from 23% to 75% male and 25% to 77% female. Research suggests incidence rates of BT are similar across males and females before aged 60 in the UK (Office for National Statistics, 2013). Four studies did not report the mean age of their participants (Budrukkar et al., 2009; Hayhurst, Mendelsohn, & Bernstein, 2011; Porter et al., 2014; Yavas et al., 2012). In those that did, ages of participants ranged from 23.00-87.50 with an overall mean age of 50.68 years. Within the UK, BTs occur relatively frequently across all age groups, with incidence increasing after 29 years (Office for National Statistics, 2013). Existing literature may therefore not be fully representative of the UK BT population regarding gender and age.

Geographically, samples were drawn from numerous countries including Australia (n=4), the Netherlands (n=2), Canada (n=1), India (n=1), Italy (n=1), Norway (n=1), Taiwan (n=1), Turkey (n=1) and the USA (n=1). The ethnicity of participants was only reported in three studies (Budrukkar et al., 2009; Lamperti et al., 2012; Porter et al., 2014).

There were a diverse range of BT classifications and definitions employed. Although tumour grade was reported consistently, some investigators appeared to use the terms 'benign' and 'malignant' to encompass different tumour groups, often failing to specify grade or classification. Accordingly, these terms may lack validity and caution is advised when comparing studies based on type of BTs. Eight studies investigated a specific BT type incorporating low grade glioma (LGG) (Aaronson et al., 2011; Hayhurst et al., 2011; Jakola et al., 2012), meningioma (Kangas et al., 2012b; van Nieuwenhuizen et al., 2007), high grade glioma (HGG) (Porter et al., 2014), acoustic neuroma (Brooker, Burney, Fletcher, & Dally, 2009) and 'benign' BTs (Tsay et al., 2012). Four studies investigated several BT categories including 'benign', LGG, HGG and glioma-not otherwise specified (Glioma-NOS) (Budrukkar et al., 2009), 'benign'/LGG and 'malignant' BTs (Ownsworth et al., 2010), 'benign' and 'malignant' BTs (Kangas, Tate, Williams, & Smee, 2012a) and grade III, grade IV and glioma-NOS BTs (Yavas et al., 2012). One study investigated recurrent BTs which were classified into 11 histologys (Lamperti et al., 2012).

Studies utilised qualitative (N = 2) and quantitative (N = 11) methodologies. Qualitative designs employed open-ended questions during focus-groups (Brooker et al., 2009) and semi-structured interviews (Hayhurst et al., 2011) to gather data. Grounded theory and thematic analysis was used in both studies to analyse results. Quantitative studies utilised cross-sectional (N = 7), longitudinal cohort (N = 3), and cohort (N = 1) designs.

Author(s), Date	Study Aims	HRQofL	Design	Participant	Response	BT	HRQofL	Other Measures	Main Findings	Quality
and Country of		Definition		Characteristics	Rate	Classification	Measure			Rating
Origin										
Aaronson et al.	To examine the	Not reported	Quantitative	BT Group	82% of the	LGG	SF-36	CFS	Female gender, epilepsy burden	52%
(2011;	prevalence of generic		Cross-	N = 195	original				and objectively assessed	
Netherlands)	and brain cancer-		sectional	Mean age $= 40.80$	sample		BN-20	Standardised	neurocognitive deficits	
	specific HRQofL			(SD = 11.60)	participated			neuropsychological	associated significantly with	
	problems and explore			62% Male				test battery - not	generic and brain cancer-	
	the sociodemographic,			39% Female				reported	specific HRQofL outcomes	
	clinical and			Mean time since					($p\leq .01$), accounting for	
	neuropsychological			diagnosis = 5.60					between 25% and 41% of the	
	factors significantly			years (SD = 3.70)					variance in LGG patients. No	
	associated with			Dutch Speaking					significant differences emerged	
	HRQofL difficulties.			Ethnicity not					when comparing generic	
	To compare LGG			reported					HRQofL profiles of LGG and	
	patients' generic								NHL/CLL patients. LGG	
	HRQofL problems			NHL/CLL Group					patients reported significantly	
	with NHL/CLL			N = 100					poorer generic HRQofL	
	patients. To compare								compared with the control	
	LGG patients' generic			Control Group					group on six out of eight	
	HRQofL with an age,			N=205					subscales and MCS.	
	gender and education									
	matched control									
	group.									
Brooker,	To gain a detailed	HRQofL	Qualitative	N = 21	29% of the	Acoustic	None	Open-ended	Physical symptoms associated	66%
Burney,	understanding of	incorporates the	design using	Mean age (range) =	original	Neuroma	utilised	interviews using	with the BT and/or its treatment	
Fletcher and	HRQofL and identify	individual's	focus-group	54.50 (29-73)	sample			focus-group	affected HRQofL, influencing	
	biopsychosocial	perception of	methodology	12 Male (57%)	participated			methodology based	psychological and social	

Table 2. Summary of the 13 reviewed studies including methodological details, key findings and quality ratings.

Dally (2009; Australia)	factors that influenced HRQofL among patients recently diagnosed with, or treated for, acoustic neuroma.	the impact of illness on functional status and physical, psychological and social wellbeing		9 Female (43%) Mean time since diagnosis (range) = 3.70 years (1-11) English Speaking Ethnicity not reported				on Krueger and Casey's (2000) principles. Grounded theory approach utilised.	 wellbeing and functional status. Patients had idiosyncratic attitudes and strategies to cope with symptoms. Psychosocial factors, particularly social support, influenced adjustment to symptoms and therefore HRQofL. 	
(2009; India)	of various factors on baseline HRQofL in adult BT patients seen in routine neuro- oncology practice before they commence adjuvant treatment.	individual's perception of physical, psychological and social wellbeing and may vary with different socioeconomic status and the environment which the	Cross- sectional	N = 237 Age = 18-40 (52%), 41-60 (42%), >60 (6%) Mean age not reported 173 Male (67%) 84 Female (33%) Mean time since diagnosis not reported Hindi and Marathi apaplying	completed measures (95%), 14 excluded (5%)	Senigit (N = 55; 22%) LGG (N = 75; 29%) HGG (N = 110; 40%) Glioma NOS (N = 17; 9%); excluded from analysis	EORIC- C30 BN-20	KF3	significantly lower in HGG patients compared with LGG patients (p=.015). Low performance status (KPS<70) was significantly associated with reduced global HRQofL scores across all histological subtypes. Within the HGG patient subgroup, high economic status was significantly associated with higher global HRQofL	0.5%
Hayhurst, Mendelsohn and Bernstein	To explore the impact of a LGG diagnosis and to address	Not reported	Qualitative	Ethnicity = Indian N = 24 Median age (range) = 47 (21-82)	Not reported	LGG	None utilised	Explorative semi- structured interviews	(p=.089). Illiterate patients had lower HRQofL across all histological subtypes (p=.005). Patients expressed devastation towards their diagnosis which dissipated within a year or	55%
(2011; Canada)	concerns regarding the diagnosis uncertainty and the impact of a			Gender not reported				conducted face-to- face or over the telephone.	following MRI demonstrating no lesion change. Continuity and trust with physicians	

	'wait and see'			Mean time since					significantly contributed to	
	approach from the			diagnosis not				Grounded theory	anxiety reductions. Patients	
	patient's perspective.			reported				approach utilised.	unanimously wished to pursue	
				Language spoken					a 'wait and see' believing	
				not reported					neurological deficits resultant	
				Ethnicity not					from intervention would greatly	
				reported					impact HRQofL. Patients	
									correlated symptoms to disease	
									severity and were vigilant for	
									deficits at which point they felt	
									intervention would be	
									warranted. Epilepsy diagnosis	
									consequential from LGG	
									diagnosis had the largest	
									HRQofL impact.	
Jakola et al.	To investigate if	Not reported	Quantitative	HRQofL Study	HRQofL	LGG	EORTC-	None utilised	Tumour eloquence was	63%
(2012; Norway)	eloquence in tumour		Cross-	N = 55	Study_		C30		significantly associated with	
	location has		sectional	Mean age = 41.00	60% of the				impaired survival (p<.001) and	
	implications for			(SD = 13.00)	original		BN-20		this relationship remained after	
	survival or HRQofL.			30 Male (55%)	sample				adjusting for established	
	To provide long-term			25 Female (45%)	participated		EQ-5D		prognostic factors skewed at	
	data on HRQofL in			Mean time since					baseline. In long-term	
	LGG patients.			diagnosis not					survivors, HRQofL was not	
				reported					significantly different in	
				Language spoken					patients with eloquent and non-	
				not reported					eloquent lesions. Regardless of	
				notreponted					1 0	
				Ethnicity not					eloquence, patients reported	
				Ethnicity not reported					eloquence, patients reported high symptom burden, with	
				Ethnicity not reported					eloquence, patients reported high symptom burden, with fatigue being the most	

				N = 153						
Kangas, Tate,	To examine whether	Not reported	Quantitative	N = 70	Not	Benign (N =	FACT-G	PCL-S	Benign BT patients reported	69%
Williams and	differences existed in		Longitudinal	Mean age = 50.57	reported	45)			improved emotional wellbeing	
Smee (2012a;	neurocognitive and		Cohort	(SD = 14.37)		Malignant (N	FACT-Br	IES-R	post-radiotherapy compared	
Australia)	psychological			32 Male (46%)		= 25)			with malignant BT patients	
	functioning, including		T2 = 3	58 Female (54%)				POMS	(p=.003). Only malignant BT	
	BT-related PTSS and		months	Mean time since BT					patients showed declines in	
	overall HRQofL,			diagnosis = 27.62				PRCI	social wellbeing post-	
	between benign and			months (SD =					radiotherapy (p=.009). Patients	
	malignant BT patients,			60.31)				SCS	with LH malignancy reported	
	pre and post			English Speaking					lower social wellbeing post-	
	radiotherapy. To			Ethnicity not				WMS-III; LM I and	radiotherapy compared with	
	explore the incidence			reported				II, and DS.	RH malignancy patients	
	and predictors of BT-								(p=.001). All patients	
	related PTSS and							WAIS-IV;	performed poorly on executive	
	HRQofL in BT							Similarities	function tests pre and post	
	patients pre and post								radiotherapy. Younger age	
	radiotherapy. To							COWAT	(<65), elevated POMS anger	
	examine the effects of								and lower FACT-G/Br scores	
	radiotherapy type and							TMT; parts A and B	pre-radiotherapy were	
	tumour laterality on								significantly predictive of	
	neurocognitive and								heightened PTSS post-	
	psychosocial								radiotherapy. Benign BT,	
	functioning.								higher FACT-G/Br score and	
									lower PCL-S and POMS	
									depression scores pre-	
									radiotherapy were significantly	
									associated with improved	

HRQofL post-radiotherapy.

Kangas,	To examine the	Not reported	Quantitative	N = 70	Not	Benign	FACT-G	IES-R	Patients with elevated PTSS	77%
Williams and	incidence of BT-		Cross-	Mean age = 57.20	reported	Meningioma			had significantly reduced	
Smee (2012b;	related PTSS in		sectional	(SD = 11.90)			FACT-Br	POMS	scores in physical, emotional	
Australia)	patients diagnosed and			Age range = 36-87.5					and functional wellbeing	
	treated for benign			16 Male (23%)				COWAT	HRQofL domains, evidenced	
	meningioma and			54 Female (77%)					more tumour symptoms and	
	investigate factors			Mean time since					experienced executive function	
	associated with PTSS			diagnosis = 53.40					deficits compared with low	
	and HRQofL			months (SD =					PTSS patients. Patients with	
				54.30)					LH BTs reported significantly	
				Range of time since					lower emotional wellbeing	
				diagnosis = 2					scores compared to RH BT	
				months - 22.6 years					patients (p=.009). Lower	
				English speaking					functional wellbeing and higher	
				Ethnicity not					POMS Confusion/	
				reported					Bewilderment scores were	
									significantly related to elevated	
									IES-R scores, explaining 31%	
									of the variance. Less time since	
									initial diagnosis, higher IES-R	
									total score and elevated POMS	
									Confusion/ Bewilderment score	
									were significantly related to	
									reduced total FACT-G/Br	
									score, explaining 57% of the	
									variance (p=.005). POMS	
									Confusion/	
									Bewilderment score part	
									mediated the relationship	

									between elevated PTSS and	
									overall HRQofL	
Lamperti et al.	To explore patient	Not reported	Quantitative	N = 81	Not	Recurrent BT	FACT-G	KPS	Distress was significantly lower	48%
(2012; Italy)	reactions towards		Cross-	Mean age $= 48.54$	reported	Diverse			in recurrent BT patients	
	diagnosis of recurrent		sectional	(SD = 13.96)		Histological	FACT-Br	HADS	compared with validation data	
	BT and their ability to			61 Male (75.3%)		Types			from cancer patients (p<.0001).	
	cope with this event			21 Female (24.7%)				PDI	Recurrent BT patients	
				Mean time since					experienced significantly	
				diagnosis = 36.74					higher depression scores	
				(SD = Not reported)					compared with normative data	
				Language spoken					from a non-clinical sample	
				not reported					(p<.012). Compared with	
				Ethnicity = Italian					validation data from BT	
									patients at first diagnosis, the	
									study sample obtained	
									significantly lower scores for	
									social (p<.001) and functional	
									(p<.001) wellbeing, but higher	
									emotional wellbeing scores	
									(p<.001). Distress (r=614,	
									p=.01) and anxiety (r=554,	
									p=.01) significantly negatively	
									correlated with emotional	
									wellbeing and depression	
									significantly negatively	
									correlated with functional	
									wellbeing (r=614, p=.01).	
Ownsworth,	To investigate the	Not reported	Quantitative	N = 30	28	Benign/Low	FACT-G	WTAR	Global cognitive function	77%
Hawkes,	influence of pre-illness		Cross-	Mean age = 51.50	completed	Grade (N =			(r=.490, p<.01) and subjective	
Chambers,	characteristics		sectional	(SD = 12.30)		18)	FACT-Br	WAIS-III; DS	impairment (r=.66, p<.01)	
Walker and	(premorbid IQ),			Age range = 28-71	measures, 2	Malignant (N			significantly and positively	
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Shum (2010;	neuropsychological			47% Male	excluded	= 12)		TMT; parts A and B	correlated with HRQofL	
Australia)	function, personal			53% Female					respectively. Higher ratings of	
	appraisals and coping,			Mean time since				HVLT	satisfaction with support were	
	and social resources			diagnosis = 5.39					significantly associated with	
	on HRQofL			years (SD = 5.40)				ROCF; recall	enhanced HRQofL (r=.50,	
				Language spoken					p<.01) and lower depressive	
				not reported				COWAT	symptoms. HRQofL was	
				Ethnicity not					significantly and negatively	
				reported				PCRS	correlated with level of	
									depressive symptoms (r=670,	
								COPE	p<.001), anxiety (r=530,	
									p<.001) and stress (r=530,	
								BSSQ	p<.01). With the exception of	
									satisfaction with support	
								DASS	ratings, the pattern of variables	
									significantly associated with	
									HRQofL differed to those	
									significantly relating to	
									depression.	
Porter et al.	To explore whether	Not reported	Quantitative	N = 26	57.40% of	HGG	FACT-G	None reported	Several non-clinical patient	63%
(2014; USA)	there is an association		Cross-	Median age (range)	the original				characteristics (having children	
	between HGG		sectional	= 57.50 (43-68)	sample		FACT-Br		under 18 years, believing the	
	patients'			13 Male	participated				prognosis was well explained,	
	sociodemographics,			13 Female			FPQLI-C		lower perception of income and	
	clinical factors and			Mean time since	Further				being single) were significantly	
	perceptions/beliefs and			diagnosis not	participants				associated with lower HRQofL.	
	HRQofL			reported	were				A longer duration from	
				English or Spanish	deceased at				diagnosis to survey completion	
				speaking					was significantly related with	

Ethnicity = Nontime of Hispanic White (N = follow up 23), Other (N = 3)

lower HRQofL (p=.0372). Frontal/temporal BTs were significantly linked to lower functional wellbeing compared with BTs at other locations. Patients HRQofL definitions differed between males and females, although both acknowledged HRQofL as

									multidimensional.
Tsay et al.	To explore the	Not reported	Quantitative	N = 58	Not	Benign	FACT-G	MDASI	Prior to surgery, symptom
(2012; Taiwan)	relationships between		Longitudinal	Mean age = 49.40	reported				distress (r=.90, p<.01) and
	symptom distress,		Cohort	(SD = 13.63)			FACT-Br	FIM	depression (r=71, p<.01)
	functional status,			Age range = 23-82					significantly and negatively
	depression and		T2 = 1 month	31 Male (53.40%)				HADS; Depression	correlated with HRQofL
	HRQofL among			27 Female (46.60%)				scale only	respectively whilst a significant
	benign BT patients			Time since					positive correlation was
	immediately prior to			diagnosis not					observed between functional
	and at one month post-			reported					status and HRQofL. Symptom
	surgery			Language spoken					distress and depression
				not reported					accounted for 80.20% and
				Ethnicity not					5.20% (p=.001 and p=.0001
				reported					respectively) of HRQofL
									variance respectively.
									Following surgery, only
									symptom distress significantly
									and negatively correlated with
									HRQofL (r=52, p<.01) and
									explained 27.10% of HRQofL
									score variance (p=.001).

71%

van	To explore whether	Not reported	Quantitative	N = 36	Not	Meningioma	SF-36	KPS
Nieuwenhuizen	additional		Cohort		reported			
et al., (2007;	radiotherapy in			Surgery only			BN-20	BADLI
Netherlands)	meningioma patients			N = 18				
	has a negative effect			Mean age = 62.60				NFS
	on neurocognitive			(SD = 11.80)				
	functioning and			Male:Female ratio =				DART
	HRQofL compared			1:7				
	with surgery only. To			Mean time since				LBT
	compare results with			diagnosis = 3.00				
	normative data from			years (SD = 1.70)				AVLT
	an age, gender and			Dutch speaking				
	education matched			Ethnicity not				WMT
	control group.			reported				
								SCWT
				Surgery and				
				<u>radiotherapy</u>				CWF
				N = 18				
				Mean age = 63.30				CST
				(SD = 10.60)				
				Male:Female ratio =				
				1:8				
				Mean time since				
				diagnosis = 7.60				
				years (SD = 6.30)				
				Dutch speaking				
				Ethnicity not				
				reported				
				Control Group				

Neurocognitive functioning and 54% HRQofL scores did not significantly differ between 'surgery only' and 'surgery and radiotherapy' patient groups, although the latter experienced more headache symptoms. In tests of memory, the 'surgery only' patient group performed significantly worse than healthy controls.

				N not reported						
Yavas et al.	To explore the effects	HRQofL is a	Quantitative	N = 118	118 (100%)	Grade III (N	EORTC-	MMSE	At baseline, male patients had	60%
(2012; Turkey)	of tumour progression	complex, multi-	Longitudinal	Median age (range)	completed	= 37) (31%)	C30		higher global HRQofL score	
	by examining	dimensional	Cohort	= 52 (19-70)	T1	Grade IV (N		HADS	than female patients, although	
	cognitive functioning,	construct and		73 Male (61.90%)	117 (99%)	= 69) (59%)	BN-20		differences were only	
	psychological distress	may incorporate	T2 = 3	45 Female (38.10%)	completed	Glioma-NOS			significant for grade III patients	
	and HRQofL of HGG	a wide variety	months	Mean time since	T2	(N = 12)			(p=.049). Global HRQofL	
	patients prior to	of issues	T3 = 6	diagnosis not	75 (64%)	(10%)			score, functional domains	
	radiotherapy, at the	including	months	reported	Completed				scores, insomnia and appetite	
	end of radiotherapy	general health,	T4 = 12	Language spoke not	T3				loss scores of EORTC-C30	
	and then throughout	physical	months	reported	40 (34%)				significantly related to disease	
	the following 18	symptoms,	T5 = 18	Ethnicity not	completed				progression. According to BN-	
	months.	functionality,	months	reported	T4				20, seizures, leg weakness,	
		toxicity,			22 (19%)				drowsiness, bladder control,	
		emotional			completed				motor dysfunction, future	
		wellbeing,			T5				uncertainty, visual disorder and	
		cognitive issues,							communication deficit	
		role							symptoms significantly related	
		functioning,							to disease progression. Global	
		social							and cognitive function scores	
		wellbeing,							significantly decreased during	
		sexual							follow-up. Significant	
		functioning,							correlations were reported	
		existential/							between global cognitive	
		spiritual issues,							function and HRQofL	
		financial status,							throughout follow-up.	
		job satisfaction							Depression and anxiety scores	
		and living							did not significantly change	
		conditions.							during follow-up. Patients who	
									underwent subtotal resection	

reported higher HRQofL compared to those with inoperable tumours (p=.027).

HRQofL=Health-Related Quality of Life; LGG=Low Grade Glioma; NHL/CLL=Non-Hodgkin's Lymphoma and Chronic Lymphatic Leukaemia; SD=Standard Deviation; SF-36=Short Form-36 Health Survey (Ware, Snow, Kosinski, & Gandek, 1993); BN-20=The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Brain Cancer Module (Osoba et al., 1996); CFS=Cognitive Functioning Scale (Stewart & Ware, 1992); MCS=Mental Component Score; BT=Primary Brain Tumour; HGG=High Grade Glioma; Glioma NOS=Glioma Not Otherwise Specified; EORTC-C30=The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Core 30 (Aaronson et al., 1993), KPS=Karnofsky Performance Index (Karnofsky et al., 1948); MRI=Magnetic Resonance Imaging: EO-5D=The EuroOol 5D (The EuroOol Group, 1990): PTSS=Post-Traumatic Stress Symptoms: FACT-G=The Functional Assessment of Cancer Therapy-General (Cella et al., 1993): FACT-Br=The Functional Assessment of Cancer Therapy-Brain (Weitzner et al., 1995); T2=Time Point 2; PCL-S=Post-Traumatic Stress Disorder Checklist-Stressor Specific Version (Weathers, Litz, Huska, & Keane, 1994); IES-R=Impact of Event Scale-Revised (Weiss & Marmar, 1997); POMS=Profile of Mood States (McNair, Lorr, & Droppleman, 1971); PRCI=Partner Responses to Cancer Inventory (Manne & Schnoll, 2001); SCS=Social Constraints Scale (Lepore & Helgeson, 1998); WMS-III=Weschler Memory Scale, third edition (Wechsler, 1997); LM=Logical Memory; DS=Digit Span; WAIS-IV=Weschler Adult Intelligence Scale, third edition (Weschler, 1997); COWAT=The Controlled Oral Word Association Test (Spreen & Strauss, 1991); TMT=Trail Making Test (Reitan & Wolfson, 1993); LH=Left Hemisphere; RH=Right Hemisphere; HADS=The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); PDI=The Psychological Distress Inventory (Morasso, Costantini, Baracco, Borreani, & Capelli, 1996); WTAR=Wechsler Test of Adult Reading (Holdnack, 2001); HVLT=Hopkins Verbal Learning Test (Brandt, 1991); ROCF=Rey-Osterrieth Complex Figure Test (Meyers & Meyers, 1995); PCRS=The Patient Competency Rating Scale (Hart, 2000); COPE (Carver, Scheier, & Weintraub, 1989); BSSQ=The Brief Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983); DASS=The Depression Anxiety and Stress Scales (Lovibond & Lovibond, 1995); FPOLI-C=The Ferrans and Powers Quality of Life Index Cancer (Ferrans, 1990); MDASI=The MD Anderson Symptom Inventory (Cleeland et al., 2000); FIM=The Functional Independence Measure Scale (Hamilton, Granger, Sherwin, Zielezny, & Tashman, 1987); BADLI=The Barthel Activities of Daily Living Index (Wade & Collin, 1988); NFS=The Neurological Functioning Scale (Order, Hellman, Von Essen, & Kligerman, 1968); DART=The Dutch Adult Reading Test (Schmand, Bakker, Saan, & Louman, 1991); LBT=The Line Bisection Test (Schenkenberg, Bradford, & Ajax, 1980); AVLT=The Auditory Verbal Learning Test (Lezak, 2004); WMT = The Working Memory Task (Sternberg, 1975); SCWT=Stroop Colour-Word Test (Lezak, 2004); CWF=Categoric Word Fluency (Benton, 1968); CST=Concept Shifting Test (Houx & Jolles, 1994); T3=Time Point 3; T4=Time Point 4; T5=Time Point 5; T1=Time Point 1; MMSE=Mini-Mental State Examination (Folstein, Folstein, & McHugh, 1975)

Definitions of HRQofL in BT literature

Only three of thirteen papers provided a definition of HRQofL incorporating both common and diverse themes (Brooker et al., 2009; Budrukkar et al., 2009; Yavas et al., 2012). All three authors acknowledged HRQofL to be multi-dimensional with a consensus on the involvement of physical, psychological and social factors. Both Brooker et al. (2009) and Budrukkar et al. (2009) emphasised the importance of an individual's perception of their illness when assessing HRQofL. Brooker et al. (2009) and Yavas et al. (2012) agreed that any HRQofL definition in BT populations should include functional status. Budrukkar et al. (2009) and Yavas et al. (2012) advocated incorporating socioeconomic status and living environment into HRQofL definitions for BT populations. Only Yavas et al. (2012) extended HRQofL definitions for BT populations to include domains of general health, toxicity, cognitive issues, role functioning, sexual functioning, existential/spiritual issues and job satisfaction.

The majority of reviewed papers failed to provide a HRQofL definition for BT populations.

Validated quantitative measurement tools utilised to assess HRQofL in BT populations

Eleven quantitative studies evaluating factors influencing HRQofL were selected from the literature because they incorporated a validated measure for BT populations. These comprised either the Functional Assessment of Cancer Therapy-General (FACT-G; Cella et al., 1993) combined with the Functional Assessment of Cancer Therapy-Brain (FACT-Br; Weitzner et al., 1995) (FACT-G/Br) or the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC- C30; Aaronson et al., 1993) combined with a brain cancer module (BN-20; Osoba et al., 1996) (EORTC-C30/BN-20). Five papers utilised the FACT-G/Br whilst two studies employed the EORTC-C30/BN-20. Two studies used the BN-20 and the Short-Form-36 Health Survey (SF-36; Ware et al., 1993). One group used a combination of the FACT-G, FACT-Br and the Ferrans and Powers Quality of Life Index Cancer (FPQLI-C; Ferrans, 1990). The remaining researchers combined the EORTC-C30, BN-20 and the EuroQol 5D (EQ-5D; The EuroQol Group, 1990). Table 3 summaries the principal aspects of HRQofL assessed by both BT validated and additional non-BT validated measures.

Authors	HRQofL Measurement Tool	HRQofL Components
	BT	Validated Measures
Cella et al. (1993)	FACT-G	Consists of four multi-item subscales that measure physical wellbeing,
		social/family wellbeing, emotional wellbeing and functional wellbeing.
Weitzner et al. (1995)	FACT-Br	Consists of 23 single item scales which assess concerns relevant to BT patients.
		Questions consider the effect of alterations in cognition, sensory processing and
		independence, measure the emotional impact of these changes, and examine the
		influence of specific physical symptoms (e.g. seizures, headaches).
Aaronson et al. (1993)	EORTC-C30	Consists of eight multi-item subscales and six single item scales. Five functional
		subscales measure physical, role, cognitive, emotional and social functioning.
		Three symptom subscales examine fatigue, pain and nausea/vomiting. Six single
		item scales consider the influence of dyspnoea, insomnia, appetite loss,
		constipation, diarrhoea and financial difficulties.
Osoba et al. (1996)	BN-20	Consists of five multi-item subscales and seven single item scales. Five multi-
		item subscales measure the impact of future uncertainty, visual disorder, motor
		dysfunction, communication deficits and emotional distress. Seven single item
		scales consider the influence of headaches, seizures, drowsiness, hair-loss,
		itching, weakness in the legs and difficulties with bladder control.

Table 3. Aspects of HRQofL assessed by BT validated and additional non-BT validated measures.

	Additional I	Non-BT Validated Measures
Ware et al. (1993)	SF-36	Consists of eight multi-item subscales that can be divided into physical and
		mental HRQofL components. Physical functioning, role limitations due to
		physical health, bodily pain and general health perceptions comprise the physical
		component summary. Vitality (energy/fatigue), social functioning, role
		limitations due to emotional health and general mental health (psychological
		distress/wellbeing) comprise the mental component summary.
Ferrans (1990)	FPQLIC-C	Consists of four multi-item subscales that measure both satisfaction with and
		importance attributed to health and functioning, social and economic wellbeing,
		psychological/spiritual wellbeing and family relations.
The EuroQol Group (1990)	EQ-5D	Consists of five multi-item subscales that measure mobility, ability to self-care,
		participation in usual activities, pain/discomfort and anxiety/depression.

Seven of eleven studies used only a BT validated HRQofL measure (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Budrukkar et al., 2009; Yavas et al., 2012; Lamperti et al., 2012). Moreover, four justified questionnaire usage including the three studies with highest quality rating (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Lamperti et al., 2012). The remaining four papers, with lower quality ratings, described a combination of BT validated and non-BT validated HRQofL tools (Jakola et al., 2012; Porter et al., 2014; van Nieuwenhuizen et al., 2007; Aaronson et al., 2011). Only two justified questionnaire usage including a BT validated HRQofL measurement (van Nieuwenhuizen et al., 2007) and employment of combined measurements (Porter et al., 2014). Although three of the eleven studies calculated internal consistency, only one incorporated an isolated BT validated HRQofL measurement (Kangas et al., 2012b). The remainder used additional non-validated assessments (Porter et al., 2014; Aaronson et al., 2011). Nonetheless, all three studies reported high levels of internal consistency using Cronbach's alpha. Kangas et al. (2012b) assessed FACT-G/Br and reported internal consistency from .76 to .85. Porter et al. (2014) analysed internal consistency for FACT-G/Br and FPQLI-C as .70 to .82 and .88 to .92 respectively. Aaronson et al. (2011) measured internal consistency for SF-36 and BN-20 as .80 to .92 and .64 to .89 respectively. Five of the six studies employing FACT-G/Br had high quality ratings (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Porter et al., 2014) whereas all studies utilising EORTC-C30/BN-20 or its components were of lower quality (Budrukkar et al., 2009; Jakola et al., 2012; Yavas et al., 2012; van Nieuwenhuizen et al., 2007; Aaronson et al., 2011).

Synthesis

Narrative synthesis of the 13 study results identified four themes: 'associations between patient factors and HRQofL', 'associations between brain tumour factors and HRQofL', 'associations between treatment factors and HRQofL' and 'associations between social support factors and HRQofL'. The theme 'associations between patient factors and HRQofL' consisted of five subthemes namely: 'socio-demographic factors', 'psychological factors', 'personal appraisals and coping factors', 'neuropsychological factors' and 'symptom factors'. All themes and subthemes were produced following identification and collation of recurring patterns and issues from the literature (Dixon-Woods et al., 2005). The subsequent narrative highlights findings according to methodological quality assessment throughout.

Associations between patient factors and HRQofL

Socio-demographic factors

Eight of the thirteen studies described socio-demographic variables in relation to HRQofL (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Budrukkar et al., 2009; Porter et al., 2014; Yavas et al., 2012; Aaronson et al., 2011). Variables included gender (N = 6), age (N = 6), educational status (N = 6), marital status (N = 4), time since diagnosis (N = 4), employment status (N = 2), socioeconomic status (N = 2), religious affiliation (N = 1), literacy (N = 1) and age of patient's children (N = 1). There appears little evidence of a major impact of sociodemographic factors on BT validated HRQofL. Six studies examined the relationship between gender and BT validated HRQofL (Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Budrukkar et al., 2009; Aaronson et al., 2011; Yavas et al., 2012). Only Yavas et al. (2012) found a significant relationship, reporting that before radiotherapy, female grade III, grade IV and Glioma-NOS patients had a lower global BT validated HRQofL score. This difference was only statistically significant for grade III BT patients.

Only four studies examined the relationship between time since diagnosis and BT validated HRQofL, reporting diverse conclusions. Findings appear independent of study quality, design and participant numbers. Kangas et al. (2012b) reported a significant relationship between reduced time since diagnosis and worse BT validated HRQofL in patients with benign meningioma. In contrast, Porter et al. (2014) found a significant association between reduced time since diagnosis and improved BT validated HRQofL in patients with HGG. The remaining studies (Ownsworth et al., 2010; Aaronson et al., 2011) failed to show any significant relationship. It appears that BT type may be important when interpreting the findings of these studies.

Two studies using different designs in disparate BT populations examined the impact of economic status with BT validated HRQofL (Tsay et al., 2012; Budrukkar et al., 2009). Only Budrukkar et al. (2009) reported significant findings, suggesting that patients within a higher economic stratum had superior global BT validated HRQofL after surgery.

Budrukkar et al. (2009) found illiterate patients with benign, LGG and HGG tumours had a lower BT validated HRQofL.

Porter et al. (2014) was the only study to investigate the relationship between age of a patient's children and their BT validated HRQofL. They reported significantly higher physical and functional wellbeing scores in HGG patients with children over 18 years. HGG patients with younger children reported lower emotional wellbeing.

Additional research is clearly needed to establish the relationship between economic status, religious affiliation, literacy and age of patient's children with BT validated HRQofL.

Psychological Factors

Seven of the thirteen studies defined psychological factors in relation to BT validated HRQofL (Kangas et al., 2012; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Brooker et al., 2009; Hayhurst et al., 2011; Lamperti et al., 2012). Topics included depression (N = 5), anxiety (N = 4), post-traumatic stress symptoms (PTSS) (N = 2), confusion/bewilderment (N = 1), anger/hostility (N = 1), stress (N = 1), body image (N = 1) and distress (N = 1).

Five studies (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Lamperti et al., 2012) reported disparate associations between depression and BT validated HRQofL. Results appeared to be influenced by study design, tumour pathology and timing of research in relation to treatment. Ownsworth et al. (2010) and Lamperti et al. (2012) described significant post-treatment negative correlations between depressive symptoms and BT validated HRQofL, whilst Kangas et al. (2012b) and Tsay et al. (2012) found no relationship between depression and BT validated HRQofL following intervention. Therefore, it seems that after intervention depression does not influence BT validated HRQofL in patients with benign BTs. Two papers examined the relationship between depression before treatment and BT validated HRQofL. Tsay et al. (2012) found a significant negative correlation between magnitude of pre-operative depression and pre-treatment BT validated HRQofL, explaining 5.2% of the variance. Kangas et al. (2012a) reported a lower depression score before radiotherapy predicted a significantly better post-radiotherapy BT validated HRQofL, accounting for 8.2% of the variance.

Four papers reported the relationship between anxiety and BT validated HRQofL (Kangas et al., 2012b; Ownsworth et al., 2010; Hayhurst et al., 2011; Lamperti et al., 2012). Only Ownsworth et al. (2010) and Lamperti et al. (2012) reported significant negative correlation between anxiety symptoms and BT validated HRQofL or emotional wellbeing respectively following surgery.

Two studies investigating the relationship between post-traumatic stress symptoms (PTSS) and BT validated HRQofL reported consistent associations (Kangas et al., 2012b; Kangas et al., 2012a). Both reported higher PTSS scores were significantly related to lower global BT validated HRQofL following treatment. Kangas et al. (2012a) also found that before radiotherapy high PTSS was associated with significantly lower pre-treatment global BT validated HRQofL score. Moreover, a lower pre-radiotherapy PTSS score predicted a significantly better post-radiotherapy BT validated HRQofL, accounting for 12.8% of the variance.

The relationship between confusion/bewilderment and BT validated HRQofL was evaluated by one paper (Kangas et al., 2012b). Higher confusion/bewilderment scores related significantly to lower BT validated HRQofL. In addition, heightened symptoms of confusion/bewilderment part-mediated the association between elevated PTSS and reduced overall BT validated HRQofL.

Three papers (Ownsworth et al., 2012; Brooker et al., 2009; Lamperti et al., 2012) investigated the influence on BT validated HRQofL of stress, body image and distress respectively. Ownsworth et al. (2012) found significant negative correlation between stress and BT validated HRQofL. The qualitative study of Brooker et al. (2009) considered that changes in perceived body image resultant from facial paralysis

compromised HRQofL. Finally, Lamperti et al. (2012) described a moderate correlation between distress and emotional wellbeing.

Personal appraisals and coping factors

Several studies investigated aspects of personal appraisals (Ownsworth et al., 2010; Porter et al., 2014; Hayhurst et al., 2011) and coping (Ownsworth et al., 2010; Brooker et al., 2009; Hayhurst et al., 2011) in relation to HRQofL.

Ownsworth et al. (2012) reported a significant correlation between perceptions of impairment and BT validated HRQofL following surgery. After treatment, Porter et al. (2014) found HGG patients who believed their prognosis had been well explained had significantly worse global BT validated HRQofL. In contrast, Hayhurst et al. (2011) investigated LGG patients' perceptions prior to treatment, using qualitative analysis, and concluded that their diagnosis had not adversely influenced their HRQofL. This disparity may be attributable to the poorer prognosis and shorter longevity associated with HGG and questions when, how and whether to provide a detailed prognosis.

When considering the relevance of coping strategy on HRQofL, the only study using quantitative analysis failed to show correlations across 13 coping domains following treatment (Ownsworth et al., 2010). However, two studies employing a qualitative design were able to identify specific coping strategies which patients considered to be important influences on their HRQofL. In the study of Brooker et al. (2009), participants described a diversity of attitudes and strategies to cope with BT symptoms at various stages of their treatment. An optimistic approach to life, a sense of purpose, engagement in meaningful activities and personal control were considered important positive influences on HRQofL. In contrast, concern over other people's opinions had a detrimental effect. The paper of Hayhurst et al. (2011) found that, before treatment, patients considered ease of access to hospital and ability to ask questions both during and between visits were major factors for reducing anxiety and improving HRQofL.

It appears that qualitative design enhanced ability to identify specific coping strategies that patients considered important influences on their HRQofL.

Neuropsychological factors

Five studies reported the relationships between neuropsychological factors and BT validated HRQofL (Kangas et al., 2012b; Ownsworth et al., 2010; Kangas et al., 2012a; Yavas et al., 2012; Aaronson et al., 2011). Variables included global cognitive functioning (N = 3), executive functioning (N = 2) and premorbid intelligence quotient (IQ) (N = 1) but only the former reported significant affiliation.

Associations between global cognitive functioning and BT validated HRQofL were evaluated in three papers (Ownsworth et al., 2010; Yavas et al., 2012; Aaronson et al., 2011), at varying treatment periods. Ownsworth et al. (2010) found a positive correlation between global cognitive function and BT validated HRQofL following surgery. Yavas et al. (2012) reported a significant correlation between global cognitive function and BT validated HRQofL pre-treatment (baseline) and four intervals over an 18 month period post-treatment. Aaronson et al. (2011) found that following treatment, the number of neuropsychological tests scored in the deviant range was associated with motor dysfunction, communication deficits and seizure symptom BT validated HRQofL domains.

Symptom factors

Five papers (Kangas et al., 2012b; Tsay et al., 2012; Brooker et al., 2009; Hayhurst et al., 2011; Aaronson et al., 2011) reported the relationship between various aspects of symptoms caused by either BTs or treatment and HRQofL at several time points.

Three papers studied relationships between general symptoms and HRQofL. Tsay et al. (2012) reported a negative impact of symptom distress on BT validated HRQofL both before surgery and at one month post-discharge. Symptom distress accounted for 80.2% of the variance in BT validated HRQofL prior to surgery and 27.1% at one month post-discharge. The qualitative study of Brooker et al. (2009) considered higher psychological wellbeing was associated with paucity of severe physical symptoms. In the qualitative paper of Hayhurst et al. (2011), patients considered that any neurological symptoms associated with future interventions would have the greatest impact on their HRQofL.

Four investigators examined relationships between specific symptoms and HRQofL. Kangas et al. (2012b) found no association between fatigue and BT validated HRQofL whilst Brooker et al (2009), studying a different BT population, considered fatigue and balance problems to have the greatest impact upon functional wellbeing. Hayhurst et al. (2011) regarded a diagnosis of epilepsy with consequent requirement for ongoing medication and loss of driving licence as being most relevant to patients' HRQofL. Moreover, Aaronson et al. (2011) highlighted that epilepsy burden was linked with future uncertainty, motor dysfunction, communication deficits and seizure symptom domains of BT validated HRQofL. Since the relationship between specific symptoms and HRQofL emerged from lower quality papers, targeted research into their impact on BT validated HRQofL is recommended.

Associations between brain tumour factors and HRQofL

Given the considerable diversity in the nature and cerebral location of BTs, eight papers (Kangas et al., 2012b; Ownsworth et al., 2010; Tsay et al., 2012; Kangas et al., 2012a; Budrukkar et al., 2009; Jakola et al., 2012; Yavas et al., 2012; Aaronson et al., 2011) explored associations between brain tumour factors and BT validated HRQofL. Variables included BT classification (N = 4), lateralisation (N = 4), location (N = 3) and disease duration (N = 3).

Of the four studies investigating the relationship between BT classification and BT validated HRQofL (Ownsworth et al., 2010; Kangas et al., 2012a; Budrukkar et al., 2009; Yavas et al., 2012), at various treatment stages, only two reported significant findings. The study of Budrukkar et al. (2009) highlighted that patients with HGG had significantly lower global BT validated HRQofL when compared with LGG, while no significant difference emerged between patients with benign and LGG. Kangas et al. (2012a) contrasted pre and post radiotherapy BT validated HRQofL scores in patients with benign or malignant tumours and reported only the latter had a decline in the social wellbeing domain (although not significant after adjustment for multiple comparisons). Although there is a degree of disparity in study results attributable to different designs and quality, it appears that having a malignant BT is associated with a lower BT validated HRQofL after treatment.

Four papers explored the influence of tumour lateralisation on BT validated HRQofL (Kangas et al., 2012b; Kangas et al., 2012a; Yavas et al., 2012; Aaronson et

al., 2012), with two reporting significant findings. When evaluating right with left hemispheric benign BTs, Kangas et al. (2012b) showed patients with left hemisphere lesions had significantly lower functional wellbeing scores post-treatment while Kangas et al. (2012a) found those with left sided tumours had greater propensity for improvement following intervention, but only in emotional wellbeing domains. When considering left and right hemisphere malignant BTs, Kangas et al. (2012a) reported a significantly greater decline in social wellbeing domain scores after treatment in those with a left hemispheric lesion while scores remained stable in patients with a right hemispheric BTs. When evaluating the influence of tumour lateralisation on BT validated HRQofL, the study quality and timing in relation to treatment appears pivotal. However, it appears that left hemispheric BTs have greater influence on BT validated HRQofL.

No association between BT location on BT validated HRQofL emerged from three studies (Tsay et al., 2012; Budrukkar et al., 2009; Jakola et al., 2012).

Three studies (Kangas et al., 2012b; Porter et al., 2014; Yavas et al., 2012) reported significant influences of disease duration on BT validated HRQofL. Investigating benign meningioma, Kangas et al. (2012b) found a shorter time interval from initial diagnosis was significantly related to lower BT validated HRQofL. In contrast, Porter et al. (2014) reported a longer duration from diagnosis to research completion was associated with lower BT validated HRQofL, physical wellbeing and emotional wellbeing in patients with HGG. Diametric findings suggest that BT type may be relevant when considering the influence of time from diagnosis on BT validated HRQofL. Yavas et al. (2012) studied the influence of time since initial diagnosis on BT validated HRQofL in grade III, grade IV and Glioma-NOS patients. As disease progressed, there was an associated fall in global BT validated HRQofL. Several HRQofL symptom domains increased with disease progression; seizure score, drowsiness, leg weakness, bladder control, future uncertainty, visual disorder, motor dysfunction and communication deficit. Consistency in deterioration of a large number of BT validated HRQofL domains is compelling, re-emphasising the importance of study timing in relation to disease progression.

Associations between treatment factors and HRQofL

Six of thirteen studies examined relationships between various treatment factors and HRQofL (Kangas et al., 2012a; Budrukkar et al., 2009; Yavas et al., 2012; Hayhurst et al., 2011; van Nieuwenhuizen et al., 2007; Aaronson et al., 2011). Subjects included nature of surgical intervention (N = 4), influence of radiotherapy (N = 3) and the impact of deferring surgical intervention (N = 1).

Of the four studies investigating the association between the extent of surgery and BT validated HRQofL (Kangas et al., 2012a; Budrukkar et al., 2009; Aaronson et al., 2011; Yavas et al., 2012), only one reported significant findings. Yavas et al. (2012) found patients who underwent a subtotal resection had significantly higher global BT validated HRQofL compared to those with inoperable tumours. However, since the study only incorporated high grade tumour patients, it remains unclear whether surgical intervention or BT severity was responsible for this difference.

Three studies (Kangas et al., 2012a; van Nieuwenhuizen et al., 2007; Aaronson et al., 2011) failed to demonstrate any significant impact of radiotherapy on BT validated HRQofL across a broad pathological spectrum using different designs.

Only the paper of Hayhurst et al. (2011) suggested deferring surgical intervention did not influence HRQofL using a qualitative design. Patients expressed a strong desire to delay surgical intervention pending a clear indication of necessity, such as radiological progression or declining functional levels. The authors' conclusion that surgery be deferred until a clear clinical indication emerges requires validation. However, their report highlights the importance of considering patients' views when evaluating surgical treatment options.

Associations between social support factors and HRQofL

Two studies (Ownsworth et al., 2010; Brooker et al., 2009) emphasised the importance of excellent social support, regardless of BT type, in enhancing HRQofL.

Ownsworth et al. (2010) found a higher rating of satisfaction with social support correlated with superior BT validated HRQofL. The qualitative paper of Brooker et al. (2009) considered social support from a variety of sources promoted psychosocial wellbeing. Support sources included interactions with family, friends, employers, work colleagues, health professionals and the broader community. Important categories of social support were practical assistance, information provision and empathy.

Additional findings in relation to methodological quality

The papers showed diverse findings and a considerable range in quality, achieving ratings between 48% (Lamperti et al., 2012) and 77% (Kangas et al., 2012b; Ownsworth et al., 2010), with a median of 63%. Most studies provided an informative summary of methodology and major findings in the abstract. Scientific background and rationale for the research was generally of high quality. Hypotheses, aims and objectives of studies were described clearly although some were compromised because of the design chosen (e.g. Lamperti et al., 2012). Participant characteristics, methods of recruitment and statistical analytical methods were predominantly reported well. In contrast, only three studies provided any definition of HRQofL (Brooker et al., 2009; Budrukkar et al., 2009; Yavas et al., 2012). Most papers provided inadequate detail relating to methodology for full replicability. There was considerable diversity in relating key results to study objectives, discussing research limitations or assessing possible bias. Interpretation of results according to study design, analytic methods or comparison with other literature was inadequate in the majority of papers. The extent to which findings could be generalised to the study population from which participants were selected was rarely discussed. Only a few authors commented adequately the implications and clinical relevance of results.

Given some elements of the checklist for evaluating study quality are design specific, quantitative and qualitative studies are considered separately.

There were 11 quantitative studies with quality ratings ranging from 48% (Lamperti et al., 2012) to 77% (Kangas et al., 2012b; Ownsworth et al., 2010), with a median of 63%. The vast majority of studies clearly described factors which influenced HRQofL. Although most studies received a high quality rating for appropriate use of statistics, this may be misleading because regression analysis was commonly featured in the statistical package. Furthermore, since seven of these studies utilised a crosssectional design, inter-variable causality could not be studied. Quality rating scores were lost for several reasons. Only three studies made significant attempts to minimise selection bias. Kangas et al. (2012a) studied patients who met stringent eligibility criteria and who consented to participate. Budrukkar et al. (2009) recruited every consecutive adult patient attending the Neuro-Oncology clinic for one year. Jakola et al. (2012) studied all patients identified from a pathology database without loss to follow-up. Only Kangas et al. (2012b), Tsay et al. (2012) and Aaronson et al. (2011) analysed participants' comparability fully by recording and, where appropriate, accounting for discrepancies in socio-demographic and clinical characteristics of patient samples. Reasons for non-participation and drop out were only stated fully in the two

studies of Ownsworth et al. (2010) and Porter et al. (2014). Some studies failed to provide adequate outcome data, an acceptable response rate or adequate follow-up information. Finally, the reason for the two lowest scores of 48% (Lamperti et al., 2012) and 52% (Aaronson et al., 2011) was concurrence of the aforementioned factors.

The two qualitative studies of Brooker et al. (2009) and Hayhurst et al. (2011) scored 66% and 55% respectively. Both the method and form of data collection was clear with analysis being relevant to the research question. However, discussion of implicit explanations surrounding the meaning of research findings was lacking while identification and explanation of association patterns or conceptual linkages were limited. Discernment of how conclusions related to or were influenced by the study context remained problematic. In neither study did the authors clarify adequately the basis of how conclusions had been derived. Finally, both papers failed to provide adequate consideration of researchers' influence on study findings.

Discussion

This systematic review is unique in attempting to describe how HRQofL is defined specifically for BT populations. Most studies failed to define HRQofL with the remainder lacking consensus. Despite these constraints, this review examined what validated and reliable quantitative measurement tools exist to assess HRQofL in BT populations. This is important because substantial use of non-validated methods possibly contributed significantly to the diverse results in current literature (Ownsworth et al., 2009). The review also examined, for the first time, how patient variables, brain tumour factors, treatment methods and social support influenced BT validated HRQofL. This evaluated whether these factors contributed in a unique way to this population. Understanding the relative influence of these variables has important clinical implications and is pivotal in directing future research. Offered definitions of HRQofL, reliable and valid measurement methods and influential factors are discussed below, however, findings should be interpreted with caution given the paucity of research and diversity of quality.

This review highlights that no accepted definition of what describes HRQofL for BT populations currently exists and it is unclear whether this may differ substantially from generic classifications in other health populations. There is a suggestion that such a designation should include physical, psychological and social domains, consistent with broader cancer literature (Bowling, 2005). Idiosyncratic additional dimensions specific to BT populations were also advocated. A lack of definition also raises queries about accepting current BT validated HRQofL measures. Review findings therefore contribute to broader deliberation surrounding difficulties in reaching a shared understanding of HRQofL, particularly given its widespread usage across diverse academic fields. Indeed, the theoretical usefulness of HRQofL as a concept is called into question. There has been a growing recognition emphasising the importance of capturing patients' subjective experiences when attempting to understand and measure HRQofL (Brooker et al., 2009; Budrukkar et al., 2009; Barcaccia et al., 2013). However, the reliability and validity of proposed measures in BT populations requires establishment, especially whether questionnaires capture direct measurement of patients' personal appraisal processes (Rapkin & Schwartz, 2004). This may only be feasible if a universal definition of HRQofL can be developed, including agreement of whether to adopt a generic or BT specific approach. Moreover, this may require both multidisciplinary and service user involvement, possibly incorporating a qualitative design as an established method for considering the personal and subjective dimensions of HRQofL surrounding health conditions. Outside this debate, it appears beneficial to

focus on what HRQofL studies recommend to ameliorate clinical practice (Koller, Klinkhammer-Schalke, & Lorenz, 2005).

To date, only two BT validated questionnaires have been developed; FACT-G/Br (Cella et al., 1993; Weitzner et al., 1995) and EORTC-C30/BN-20 (Aaronson et al., 1993; Osoba et al., 1996). These questionnaires were designed and validated in the USA and Canada respectively, defining HRQofL generically from WHO criteria, but reviewed study populations had diverse geographical, cultural and social domains which challenges the reliability and validity of scores obtained. Yavas et al. (2012) emphasised that HRQofL perceptions and the ways health problems are expressed vary according to country. Accordingly, these issues may explain the inconsistencies and diversity of reported findings. Most of the higher quality research preferred the extensively validated FACT-G/Br, which appeared to have higher internal consistency, but there have been no large, well-designed studies investigating HRQofL using either method (Liu, Page, Solheim, Fox, & Chang, 2009). These BT validated measures focused predominantly on broad aspects of physical, social, emotional and functional wellbeing, incorporating specific physical symptoms relevant to BT populations and the impact of changes in independence. Several researchers utilised additional non-validated HRQofL measures, possibly to capture aspects of HRQofL not considered by current BT validated HRQofL questionnaires. Addition of the SF-36 (Ware et al., 1993) allowed greater examination of the influence of emotional health on HRQofL and a patient's ability to maintain previous activities. Use of the EQ-5D (The EuroQol Group, 1990) enabled detailed assessment of how independence may be affected by a BT in terms of ability to self-care and participate in usual activities and identified the presence of anxiety or depression. Incorporation of the FPQLIC-C (Ferrans, 1990) emphasised spiritual aspects of HRQofL, including a reflective aspect ascertaining satisfaction with and importance placed on various HRQofL domains. Therefore, considerable work is

needed to design and validate a more robust and comprehensive quantitative HRQofL measure before undertaking substantive research in BT patients. When undertaking such a validation, it will be essential to establish whether any statistically significant change in HRQofL score from baseline translates into a clinically meaningful alteration in patient perceptions (Maringwa et al., 2011). Moreover, the applicability of any HRQofL measure will require validation across geographical, culture and social domains (Budrukkar et al., 2009). Another concern that has been raised is the ability of a patient with a BT to assess their HRQofL, particularly when there is cognitive disturbance (van Nieuwenhuizen et al., 2007). However, there appears little benefit from adding the ratings of carers and practitioners as they are unreliable sources of HRQofL assessment (Ownsworth et al., 2010). While this re-emphasises the subjectivity of how different groups of individuals view health conditions, this review suggests that patients with a BT can provide useful insights about their HRQofL. In order to resolve these discrepancies, qualitative research may be preferential to augment understanding of the nature and magnitude of these differences in perceptions of illness and treatment.

This review aimed to identify factors that influenced HRQofL in patients with BT with the aspiration to suggest areas for interventions. Despite the varying quality and diverse designs of studies examined, it emerged that numerous factors appeared to impact HRQofL. Where more than one paper discussed specific factors, no association was consistently reported between age, educational status, employment status, executive functioning, site of BT or radiotherapy treatment and HRQofL. It was not possible to draw consistent conclusions about the impact of any other socio-demographic factors, post-treatment depression, peri-treatment anxiety, fatigue, BT type, disease duration or extent of surgery and HRQofL. These inconsistencies accord with conclusions from a previous review (Ownsworth et al., 2009). The implications of reported contributory factors from this review will now be discussed in detail.

The theme examining 'patient factors' highlighted that psychological features of pre-treatment depression and PTSS including confusion/bewilderment were consistently influential on BT validated HRQofL. Furthermore, personal appraisals and coping strategies, the neuropsychological variable of global cognitive functioning and symptom factors of physical symptom distress and epilepsy affected HRQofL.

Current evaluation confirmed the predictive influence of pre-intervention depression on peri-treatment HRQofL reported in Ownsworth et al's. (2009) review. However, it could not confirm findings that pre-treatment depression predicted longterm HRQofL, possibly consequent upon their use of non-validated BT instruments. Moreover, this review considered the influence of post-treatment depression on BTvalidated HRQofL, but findings were inconsistent. Research is needed to settle this dilemma given high depression prevalence after treatment (Arnold et al., 2008) and interactions between depression and personal appraisals when adjusting to diagnosis and intervention (Kangas et al., 2012a). The severity of depression should also be considered since this may influence the relative merits of pharmacological and psychological interventions (Kilbride, Smith, & Grant, 2007).

Both before and after treatment, PTSS magnitude was consistently predictive of post-intervention BT validated HRQofL. Uniquely, high PTSS was associated with reduced BT-validated HRQofL both before and after treatment. This relationship appeared to be mediated in part by accompanying heightened symptoms of confusion/bewilderment. All three studies examining personal appraisals confirmed a significant relationship to HRQofL. However, direction of influence varied highlighting idiosyncratic patient responses to BT diagnosis, prognosis and treatment. This is the first review to report a significant relationship between coping strategy and HRQofL in BT populations. Interestingly, an association was identified using qualitative design, perhaps highlighting the individualistic nature of response to illness. Retained global cognitive functioning was reported regularly as enhancing BT validated HRQofL but no link existed for executive functioning. Perhaps the most compelling review finding was a consistent compromising influence of elevated physical symptom distress and poor epilepsy control on HRQofL. Unlike the previous review of Ownsworth et al. (2009), the current review found a more variable relationship between increased fatigue and reduced BT validated HRQofL, possibly reflecting greater methodological diversity.

Overall, this review of 'patient factors' endorses conclusions from wider cancer populations that individuals' personal appraisals and coping strategies are predictive of HRQofL domains, especially emotional wellbeing (Jenkins & Paragment, 1998). Furthermore, findings are consistent with current understanding of the interdependency and interactions of these 'patient factors' in influencing BT morbidity (Hamam-Raz et al., 2007; Arnold et al., 2008; Dijkstra et al., 2009). Despite complex variable interactions, subjective appraisals throughout BT diagnosis and management appear pivotal for short and long term adjustment, probably being affected by the patient's level of global cognitive functioning and symptom distress.

Cognitive models of trauma emphasise how personal appraisals are influential when adapting to a potentially life threatening experience (Ehlers & Clark, 2000). Evidence suggests that up to one-third of individuals receiving a life threatening diagnosis will experience symptoms compatible with post-traumatic stress disorder (PTSD) (Kangas, Henry, & Bryant, 2002). Historically, functioning alterations in patients with acquired brain injury were attributed solely to the neurological impact of their pathology and only recently has the potential of trauma reactions been considered. Should a patient internalise their BT as potentially life threatening or a danger to their physical integrity, there may be increased susceptibility to experiencing PTSS from either diagnosis or treatment experiences. Partial mediation by heightened confusion/bewilderment symptoms of elevated PTSS and reduced BT validated

HRQofL, reported in this review, is also consistent with the cognitive processing model of trauma (Ehlers & Clark, 2000). In this theory, stress reactions arising from traumatic events are purported to be partially maintained when a patient's cognitive resources are inadequate. Global cognitive impairment may enhance this contribution, as suggested by associations with reduced HRQofL. Consequently, the inability to utilise adaptive coping and problem solving strategies may ensue, which could be aggravated by concurrent chronic disease and/or treatment side effects, especially symptom distress or epilepsy. However, wider literature indicates caution when suggesting the presence of PTSD in oncology populations. Questionnaire-based methods for assessing PTSD are often used in isolation and may be inappropriate for patients with chronic conditions as content of 'items' are unspecific to illness or treatment. Previous studies investigating PTSD in health populations that only incorporated quantitative measurement have yielded a higher proportion of false positives when compared to those utilising an additional diagnostic interview (Kwakkenbos, Coyne, & Thombs, 2014). The presence of PTSS in BT populations reported in this review was also identified through quantitative assessment using the IES-R questionnaire (Weiss & Marmar, 1997). However, in an attempt to reduce the limitations associated with quantitative methodology, participants also completed questionnaires with specific reference to their BT diagnosis and treatment experiences to capture relevant PTSS. Nevertheless, it is unclear whether the presence of PTSS were related aetiologically to PTSD, another psychological condition or multiple syndromes. Accordingly, research utilising a combination of diagnostic interview and questionnaire approaches appears imperative to ascertain whether PTSD is truly present and if so, how it influences HRQofL in BT populations. If PTSD is identified, future prospective, longitudinal based studies will be required to ascertain the relative contribution of other biopsychosocial factors to PTSS

and HRQofL as only partial mediation by confusion/bewilderment symptoms was evident.

The findings of this review advocate the importance of screening a patient's psychological and neurocognitive functioning to allow appropriate interventions that improve HRQofL. There appears utility for a multidisciplinary approach whereby health professionals become skilled in detecting the aforementioned patient factors that influence BT validated HRQofL. Potential exists for psychotherapy and rehabilitation interventions to target maladaptive personal appraisals and support the development of effective coping strategies (Ownsworth et al., 2010). By establishing treatments for coexisting physical symptoms and defining prioritisation strategies to alleviate most concerning symptoms, HRQofL may be enhanced (Tsay et al., 2012). Evidence supports the efficacy of therapeutic approaches for improving a patient's symptom selfmanagement within brain injury (Bombardier et al., 2009) and cancer (Greer et al., 1992) populations. To date, no published controlled trials for the treatment of psychological or cognitive problems within BT populations exist (Kangas et al., 2012b). Nevertheless, evaluation of rehabilitation techniques suggests that BT patients experience functional gains comparable to individuals with other forms of brain injury (Greenberg, Treger, & Ring, 2006). Given the scarcity of BT specific treatment strategies (NICE, 2006), it could be useful to assess whether existing cancer and brain injury support services meet BT patients' care needs from a cost-economic perspective (Ownsworth et al., 2010). This would also enable determination of additional specific requirements for BT interventions. Other non-pharmacologic treatments, especially exercise, are also thought to improve HRQofL and should be evaluated in BT populations (Jones et al., 2007). Furthermore, effective cognitive training modules for memory, reasoning, and speed of processing have been developed for non-cancer

participants (Willis et al., 2006) that might afford an extended application to BT patients.

The theme examining 'tumour factors' identified that laterality influenced BT validated HRQofL. Although there were inconsistencies in the literature concerning BT type, it emerged that people with malignant BTs may have lower HRQofL. This review could not identify consistently any 'treatment factors' that influenced HRQofL. However, the assertion of Hayhurst et al. (2011) that delaying surgery may optimise HRQofL is interesting.

The findings that left hemispheric lesions had a greater adverse impact on BT validated HRQofL is consistent with inter-hemispheric emotional balance theory (Burton, 1999). This posits that the right hemisphere processes negative emotional information while the left hemisphere attends to positive emotional content. Accordingly, a left hemispheric lesion would impose greater detrimental influence. Moreover, Klein, Heimans and Aaronson (2002) reported cognitive impairment is more frequent with dominant hemisphere tumours (which are usually left-sided) which may further compromise HRQofL. Although the review identified conflicting influences of BT type, there was a trend suggesting patients with malignant tumours suffered poorer BT validated HRQofL. Accordingly, stability of a patient's clinical status may be more relevant than tumour malignancy in influencing HRQofL and therefore explain inconsistencies. Nevertheless, it is problematic to differentiate the relative influences of tumour factors and treatment variables on HRQofL. Magnitude and nature of medical intervention is influenced by tumour type, size, multi-focality, location and eloquence (Jalali & Dutta, 2012). Furthermore, previous studies failed to control for the impact of chemotherapy or corticosteroid effects on HRQofL (Osoba et al., 2000; Kirschbaum, Wolf, May, Wippich, & Hellhammer, 1996). Consideration should also be given to the psychological burden afforded by an impending threat of tumour recurrence and its

consequences on treatment. The review highlights how important it is to control for these confounding variables when investigating the impact of specific tumour or treatment factors on HRQofL.

The paucity of evidence that 'tumour factors' and 'treatment factors' influence BT validated HRQofL emphasises targeting of aforementioned 'patient factors', particularly personal appraisals which may be amenable to modification. Empowering patients to make decisions regarding their treatment through consideration of their personal preferences may explain how delaying surgery was associated with improved HRQofL (Hayhurst et al., 2011). Edvardsson, Pahlson and Ahlstrom (2006) demonstrated a positive impact when BT patients were permitted to participate and influence decisions surrounding their treatment. The Common Sense Model (CSM; Leventhal, Nerenz, & Steele, 1984) accords with these findings, conceptualising illness perceptions within a "self-regulation framework", where following disease onset, patients develop organised beliefs directed at managing their health condition. Subjective representations of what is occurring physically and idiosyncratic perceptions surrounding the possible consequences of treatment can be divided into cognitive and emotional categories that motivate coping and decision making behaviour. Despite acknowledgement that illness perceptions affect clinical and psychological outcomes in chronic health conditions (Moss-Morris et al., 2002), including HRQofL (Griva, Jayasena, Davenport, Harrison, & Newman, 2009), research has yet to examine potential influences within BT populations. Future investigation appears paramount given this review's emphasis on acknowledging patients' personal appraisals and recommendation of a combined interview-questionnaire approach when assessing illness beliefs (Reynolds, Broadbent, Ellis, Gamble, & Petrie, 2007).

The theme evaluating 'social support factors' confirmed significant enhancement of HRQofL from social support at all stages of treatment regardless of

tumour type. Relevant categories of support were practical assistance, information provision and empathy from a variety of sources.

Few studies have evaluated social support effects on HRQofL within BT populations. Nevertheless, review findings endorsed the well-established reports within oncology (Helgeson and Choen, 1996) and trauma (Ozer, Best, Lipsey, & Weiss, 2003) literature that social support positively impacts psychological adjustment to a lifethreatening diagnosis. In particular, access to information pertinent to the diagnosis and treatment of BT, including early screening and ongoing monitoring of psychological wellbeing, is crucial (Ownsworth et al., 2009). This would allow triaging of patients and their families to suitable support services in accordance with the cancer service delivery model of Hutchison, Steginga and Dunn (2006). The magnitude of any intervention may be based on current need but then adapted for changing care requirements over time. Specialist training of professionals in delivering information and providing support concerning existential issues is recommended (Strang, Strang, & Ternestedt, 2001). Methods for communicating distressing information to patients with BT still requires investigation. Various social support services are discussed within the BT literature, including stress reduction interventions (Keir, Guill, Carter, & Friedman, 2006), telephone follow-up or counselling (Sardell, Sharpe, Ashley, Guerrero, & Brada, 2000) and BT support groups (Barr, 2003) but systematic evaluation is also warranted to ascertain their impact on HRQofL.

Strengths, Limitations and Methodological Quality

This review requires interpretation in the light of both strengths and limitations. It is the only systematic review, to date, that evaluates how HRQofL has been defined specifically for BT patients. The absence of a comprehensive consensus on how to define HRQofL compromised reliability and calls into question the validity of its findings in BT populations. Nevertheless the review remains a unique examination of factors influencing only BT validated HRQofL. Results allow future research recommendations and provide useful insights for developing clinical practice.

Despite significant attempts to tailor the search terms, many results were yielded originally, even after application of limiters and removal of duplicates. Consequently, only abstracts were considered initially as otherwise many papers emerged as irrelevant or inappropriate. While search methods aimed to ensure that only peer reviewed articles specifically focusing on factors influencing BT validated HRQofL were included, it remains possible that relevant papers may have been omitted. However, this approach ensured the quality of reviewed studies was maximised, although findings remained subject to publication bias (Rothstein, Sutton, & Borenstein, 2005). Accordingly, only 13 articles were identified for inclusion and analysis. This probably highlights the sparsity of HRQofL research in BT populations but could also reflect the search strategy invoked. Results are therefore constrained by limited literature and conclusions should be interpreted with caution.

A quality assessment tool comprising five combined measures enabled thorough evaluation of article sections, permitting rating comparisons across designs. While amalgamating measures may have compromised validity, two independent assessors reported moderate inter-rater reliability for this combined checklist. However, psychometric properties remained untested.

Regarding sampling methods, a minority of studies recruited large, representative samples (>100), based on consecutive admissions or multisite participation. Most papers were meritorious in recording demographic variables. However, ethnicity was rarely considered and warrants inclusion in future research. Despite the large number of studies being considered through initial searches, no paper incorporated had origins within the UK. Most studies were constrained by having small, heterogeneous samples, disparate tumour classifications and varied recruitment times since diagnosis. Although this permitted examination of potential HRQofL associations across the disease course, there is limited generalisability to other BT populations. Furthermore, use of 'convenience' samples from single hospital sites may have increased selection bias due to non-randomisation. Small samples may have reduced statistical power, especially for correlational analysis, perhaps limiting ability to detect weaker associations. Moreover, participant limitations often precluded use of multivariate analysis confining interrogation to univariate approaches. Consequently, independent and interactive influences of variables in predicting BT validated HROofL were not explored or adequately controlled for. Prospective longitudinal studies highlighted difficulties in collecting and interpreting data in a population with high prevalence of neurological morbidity and disease progression. Patients with severe HRQofL reductions and neurological deficits are more likely to have declined participation, thereby evoking underrepresentation. This risks overestimation of HRQofL scores. No study included older adult participants (>65) when examining age effects on BT validated HRQofL. Comparison across all age groups is crucial to establish potential age-related influences, especially cohort effects.

Studies employed diverse methodological designs when examining factors related to HRQofL. Cross-sectional papers examined statistical associations mainly through correlational, between-group or within group analysis omitting investigation of predictive causal relationships. Such designs also constrained insight into how patterns of HRQofL may change over time. Where prospective methodologies were utilised, most follow up assessments were short (\leq 3 months), possibly reflecting disease progression. Paucity of available qualitative research studies limited understanding regarding processes involved in a patient adjusting to BT diagnosis and subsequent

treatment. Indications that confounding variables affected HRQofL also limit confidence regarding the reported influence of specific factors. Quantitative studies failed to report power or sample size calculations increasing the risk of type II errors (false acceptance of null hypothesis) in the literature reviewed.

Considerable diversity existed in how emotional status was measured. Many self-assessment tools were employed that had been developed for general clinical populations or individuals with neurological disorders or cancer. Since many biopsychosocial variables appear interdependent in BT patients, the validity of tools utilised remains unclear (Litofsky et al., 2004) and may explain disparate findings concerning the influence of psychological factors on HRQofL. Accordingly, multimodal assessment methods utilising self-report questionnaires and diagnostic interviews appear preferential when investigating emotional stress in BT patients.

Directions for Future Research

This review highlighted the paucity of current literature on HRQofL in BT populations. It emerges that to optimise future research, an internationally accepted HRQofL definition may require development which could also assist verification of the reliability and validity of proposed tools in BT patients. Review findings suggest considerable work is still required to design and validate more robust and comprehensive HRQofL measures before undertaking substantive quantitative research in BT populations. Results also recommend input from both multidisciplinary teams and service-users. However, the subjective nature of each patient's HRQofL report may compromise the ability to reach consensus over a universal definition or measurement. Specifically, a patient's report of HRQofL at a given period in time may be influenced by concurrent life experiences and personality variables. It is also clear that a large
number of interdependent biopsychosocial factors influence HRQofL but each patient may attribute differing levels of importance to these. This subjectivity calls into question the feasibility and practicality of reaching a HRQofL definition.

Given the anticipated difficulty of defining and measuring HRQofL, an alternative approach is suggested by positive psychology literature emphasising the multidimensional construct of wellbeing. Two approaches are used to define wellbeing: the hedonic tradition, accentuating constructs of happiness and life satisfaction, and the eudemonic tradition, emphasising positive psychological functioning and human development (Dodge, Daly, Huyton, & Sanders, 2012). Emphasis is shifted away from temporal HROofL assessment and towards the conditions and processes that contribute to a person's development, fulfilment and optimal functioning. Seligman's (2011) theory posits that this 'flourishing' life consists of the pursuit and attainment of positive emotion, engagement, relationships, meaning and accomplishments (PERMA). Jayawickreme, Forgeard, and Seligman (2012) further integrate wellbeing traditions, proposing an 'Engine of Wellbeing' that accentuates and qualifies the conditions for optimal functioning. Authors distinguish between inputs (resources and traits that influence wellbeing), processes (internal states that influence choice/decision making) and outcomes (behaviours that reflect wellbeing). A clear definition and theoretical understanding of wellbeing emerges from this approach allowing potential for both quantitative and qualitative research (Dodge et al., 2012). However, to date, there have been no studies examining wellbeing in BT populations.

Despite the possibility of alternative approaches, it is clear that to date, HRQofL assessment has been the predominant methodology in BT populations. This still represents a shift away from historic predominant medical attitudes, leading to a greater holistic consideration of the person. Accordingly, it appears meritorious to find ways of

improving study methodology using this approach to facilitate progression of future meaningful and comparable research.

Most studies employed cross-sectional designs with limited statistical power. Larger high-quality prospective reports are needed to better describe the long-term HRQofL of BT patients, particularly in UK populations. Repeated evaluations at predetermined regular intervals would enable HRQofL assessment throughout the disease course and ascertain relative influences of biopsychosocial factors at different illness phases. This may provide guidance concerning changing support needs of patients and their families. Data should be analysed using methods that allow for response shifts, which are natural temporal changes in patients HRQofL perceptions due to changing internal standards when faced with a life-threatening illness. Furthermore, drop out to follow up should be documented as disease progresses. Without such acknowledgment, results from longitudinal research may incorrectly attribute HRQofL changes to other external factors. Models accounting for this phenomenon have been proposed (Schwartz et al., 2006).

Future studies should recruit an adequate sample size to fulfil the assumptions and requirements of multivariate analysis. This is essential to allow the mediating and moderating effects of predictors to be tested, particularly when relating PTSS with BT validated HRQofL. Collaboration between research groups may assist with patient recruitment, given the lack of feasibility for a single site to obtain an adequate sample size, allowing control for differences in geographical location, treatment regimens and support.

The study of HRQofL is complex given large numbers of interdependent biopsychosocial factors and interrelating HRQofL domains. This may explain why many studies have produced mixed results. In order to account for confounding variables, a focused question, appropriately evaluating adequately powered randomised

groups, prospectively measured at pre-specified intervals during management, is necessary to account for interactions. Researchers should consider employing a core of universally accepted BT validated measures to facilitate comparison of multiple study findings through meta-analysis.

Specific areas requiring further exploration include the role of personal appraisals and coping strategies when adjusting to BT diagnosis and treatment. Accordingly, the impact of illness perceptions on HRQofL in BT populations is worthy of focused research given their impact in other chronic health conditions. Furthermore, the impact of various types of social support (i.e. emotional, informational and instrumental) warrants investigation, with particular focus on appropriate methods for communicating distressing information. Qualitative methodology may be preferential when studying these variables and could aid in directing management strategies. Moreover, research investigating the effects of individual (particularly fatigue) and cooccurring symptoms on HRQofL appears beneficial. More comprehensive batteries of neuropsychological tests are also required in future studies to ascertain relevant cognitive factors associated with HRQofL.

Few psychological interventions or rehabilitation programmes have been specifically evaluated for patients with BT. Both the efficacy and cost-effectiveness of treatments which target important health care needs require assessment, including the efficacy of current methods used in patients with other brain disorders or cancer populations. To maximise validity, it is important to employ systematic research designs, including Randomised Control Trials (RCTs), as guided by international standards (Moher, Schulz, & Altman, 2001).

Conclusions

In conclusion, this systematic literature review aimed to ascertain how HRQofL was defined within BT literature. An attempt was made to identify existing quantitative measures that are considered to reliability and validly assess HRQofL. Thereafter, relevant factors influencing HRQofL in BT patients were reported. No clear definition of HRQofL emerged. Most recent studies utilised either the FACT-G/Br (Cella et al., 1993; Weitzner et al., 1995) and EORTC-C30/BN-20 (Aaronson et al., 1993; Osoba et al., 1996) however, several papers also incorporated other non BT validated HRQofL measures, possibly to capture aspects of HRQofL omitted by current BT validated HRQofL questionnaires. Future research may be compromised unless a clear HRQofL definition is developed enabling description of a comprehensive widely accepted measurement tool. This review also highlighted the impact of personal appraisals and processes involved in a patient's ability to adjust to BT diagnosis, prognosis and subsequent treatment. Future research exploring subjective perceptions appears necessary and qualitative methodology offers an important approach. Given the aforementioned constraints, quantification of the efficacy and cost-effectiveness of treatments currently used in patients with cancer or other brain disorders is probably more realistic than attempting to develop specific interventions for a BT population.

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Part Two

Empirical Study

Exploring patient-neurosurgical team inter-relationships throughout the perioperative period of awake craniotomy

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This paper is written in the format ready for submission to Brain Impairment. Please see Appendix A for the guidelines for contributors.

Word Count (Excluding References): 27,913

Abstract

Previous research suggests optimal patient-practitioner relationships are paramount to enhance patients' experiences of awake craniotomy (AC). This knowledge underscores the need for development of enhanced perioperative relationships between patients and relevant professionals, with clinical communication being important. This study aimed to investigate the lived experience of AC and perioperative interactions for both patients and neurosurgical team members. A retrospective exploratory qualitative design using interpretative phenomenological analysis (IPA) was employed. Multicentre recruitment occurred for both patient and neurosurgical team member groups, each consisting of eight participants, who shared their experiences through semistructured interviews. Analysis revealed four superordinate themes and six subordinate themes for the patient group and three superordinate and seven subordinate themes within the neurosurgical team member group. Development of positive relationships, hope and trust was paramount to enable coping and optimise the AC experience. This required contextually appropriate communication behaviours at each operative stage based on patients' preferences, apprehension levels and ability to process information. Findings advocate the co-ordination of patient-centred holistic care, informed by a biopsychosocial model, to optimise relationship building and team performance, given the limitations of a medical model to meet the diverse support needs of patients undergoing AC across their illness and treatment journey.

Key Words: brain tumour, awake craniotomy, relationships, experiences, interpretative phenomenological analysis

Introduction

Primary brain tumours (BT) are a significant source of morbidity and mortality with an estimated 6,500 people being diagnosed annually in the United Kingdom (UK) (NICE, 2006). They are classified based on cell/tissue type, location and degree of malignancy (Ownsworth, Hawkes, Steginga, Walker, & Shum, 2009). Low-grade (I-II) tumours are characterised by slow growth rates and relatively distinct boundaries (Kalkanis, Quinones-Hinojosa, Buzney, Ribaudo, & Black, 2000). High-grade (III-IV) tumours are malignant and defined by rapid growth rates, infiltration to nearby brain tissue and higher risk of recurrence following treatment (Ownsworth et al., 2009). Frequent symptoms include headache, nausea, vomiting, seizures and fatigue, in addition to motor, sensory and cognitive deficits (Goebel, Stark, Kaup, von Harscher, & Mehdorn, 2011). Only recently has research into the psychological impact of having a BT been undertaken. The relatively poor prognosis and invasive treatment increases patient distress levels (Goebel et al., 2011) yet unmet psychological care rates are high, particularly in emotional, social and spiritual domains (Janda et al., 2008). Patient reactions towards diagnosis and subsequent treatment appear idiosyncratic and unpredictable (Goebel et al., 2011).

Recently, there has been renewed concern that resection of eloquent BTs under general anaesthetic risks invoking unnecessary damage to the adjacent brain. Awake craniotomy (AC) offers the possibility of improving survival by allowing extensive tumour resection while avoiding functional loss (Goebel, Nabavi, Schubert, & Mehdorn, 2010). The awake patient undergoes cortical and subcortical intraoperative mapping which identifies and preserves eloquent sensory and/or motor areas, thereby maximising tumour removal while minimising the risk of permanent deficits (Wahab, Grundy, & Weidmann, 2011). The AC procedure may be conducted in one of two ways.

Either the patient undergoes general anaesthesia for most of the procedure and is awakened only for mapping phases (an 'asleep-awake-asleep' protocol) or the patient remains awake with minimal sedation throughout the entire operation (an 'awake' protocol) (Palese, Skrap, Fachin, Visioli, & Zannini, 2008; Manchella et al., 2011). AC has been described as preferential, safe and efficient, with fewer intensive care admissions and shorter hospital stays, thereby reducing costs (Serletis & Bernstein, 2007). Patient advantages are thought to encompass decreased likelihood of tumour dedifferentiation, improved accuracy of pathological diagnosis and reduction of intracranial pressure, thereby lengthening time to recurrence and prolonging survival (Goebel et al., 2010).

The literature to date has not fully considered the patients' idiosyncratic psychological reactions towards the procedure and aftercare. Little is known about patient experiences of the surgery. Furthermore, there is a paucity of literature examining how neurosurgical team members experience AC and manage the technical aspects of surgery while communicating with an awake patient.

The majority of published studies investigating AC experiences utilise quantitative or mixed-method approaches and examine patient satisfaction (Danks, Rogers, Aglio, Gugino, & Black, 1998; Goebel et al., 2010), acceptance (Wrede et al., 2011) and tolerance (Whittle, Midgley, Georges, Pringle, & Taylor, 2005; Wahab et al., 2011) during the procedure. Danks et al. (1998) reported 57% of interviewed patients were satisfied during their AC. Similar findings were described by Goebel et al. (2010) with two thirds of patients being fully content during the operation. Patient acceptance of AC compared to craniotomy under general anaesthetic was investigated by Wrede et al. (2011), indicating a self-reported preference for AC, particularly in postoperative pain and physical disorder domains. In terms of patient tolerance, Whittle et al. (2005) found that patients coped well with AC. Results were endorsed by Wahab et al. (2011) who further stated that a successful procedure is promoted by well-informed patients who are calm, comfortable and co-operative throughout their operation.

Overall, the literature suggests that most patients experience a pleasant AC, with pain being the predominant source of discomfort. However, these studies failed to investigate the spectrum of psychological reactions experienced or explain why some patients tolerate and others struggle with AC. Caution is also warranted regarding reported results due to methodological limitations. Selection bias was indicated, with Goebel et al. (2010) choosing psychologically resilient patients. Wrede et al. (2011) utilised a measure developed and validated on participants undergoing general surgery and not neurosurgery, thereby potentially missing specific issues relating to patients with BT. One study also used a questionnaire designed by the authors which was not validated (Wahab et al., 2011). Additionally, conclusions were potentially compromised by lack of transparency (Whittle et al., 2005) or biased through a surgical team member conducting data collection (Danks et al., 1998). Sample sizes were small, ranging from 15 (Whittle et al., 2005) to 60 (Wahab et al., 2011) participants, thereby reducing statistical power. Finally, three out of five studies (Whittle et al., 2005; Wrede et al., 2011; Wahab et al., 2011) utilised only questionnaires to explore patient experiences which may have restricted exploration of accounts, thereby limiting the richness of results.

Previous research appears limited and studies have started adopting qualitative methodologies to obtain more comprehensive and personal accounts of AC experiences. To date, there have been four qualitative reports exploring patient experiences (Palese et al., 2008; Khu et al., 2010; Manchella et al., 2011; Fletcher, das Nair, Macniven, Basu, & Byrne, 2012) and one examining instrument nurses perceptions of AC (Palese & Infanti, 2006). Current literature highlights the intrinsically individual and complex

nature of AC experiences and places importance on establishing meaningful patientpractitioner relationships through optimal communication.

Palese et al. (2008) utilised phenomenological analysis to explore patient experiences before, during and immediately after AC. Preoperatively, coping strategies were based on external resources, but a patient preoccupation about their intraoperative role took precedence. Intraoperatively, patients concentrated on required tasks, which absorbed other thoughts and emotions. Maintaining self-control appeared important and was facilitated by information updates from the neurosurgical team. Postoperatively, patients were less concerned about prognosis and more interested in discovering any future disabilities resultant from the procedure.

Khu et al. (2010) used thematic analysis to identify patient perceptions of AC. Preoperatively, patients appreciated adequate information that enabled informed decisions and indications of what to expect during surgery. Interestingly, trust in their neurosurgeon greatly influenced decision making. Patients were more concerned about their disease than the procedure, contrasting previous findings (Palese et al., 2008). Differences appear unclear and cannot be ascertained from report methodologies but perhaps highlight the idiosyncratic nature of patient experiences. Intraoperatively, patients found it reassuring speaking with the neurosurgeon which impacted positively on perceived support levels and reduced anxiety. It was thought being an integral part of the treatment team sustained patient autonomy. Postoperatively, patients wanted more information prior to discharge.

Manchella et al. (2011) adopted thematic analysis to explore patient views of AC. Preoperatively, patients demonstrated a good understanding of AC rationale which impacted beneficially on preparedness for surgery. Confidence was further enhanced by preoperative discussion of basic surgical and anaesthetic protocols. Intraoperatively, most patients described positive experiences, with a minority describing pain,

discomfort and claustrophobia. Continual physical contact with a neurosurgical team member was reported to reduce anxiety. Following surgery, most patients were satisfied although one reported negative views due to permanent neurological deficit.

Only one study has explored patients AC experiences in UK populations using Interpretative Phenomenological Analysis (IPA) (Fletcher et al., 2012). The 'relationship with the neurosurgeon' emerged as a core theme. Similar to the findings of Palese et al. (2008) patients used self-preservation or coping strategies as protection against procedure apprehensions. Patients relied on the neurosurgeon to make treatment decisions as a coping mechanism, placing an extreme amount of trust in them. Similar to Khu et al. (2009), patients reported a pleasant procedure, utilising the neurosurgeon and neurosurgical team relationship to contain anxieties. Despite dissatisfaction over inadequacy of preoperative information, patients avoided seeking it as a selfpreservation strategy, relying instead on the relationship for knowledge.

The phenomenological investigation of Palese and Infanti (2006) is the only qualitative study exploring the experiences of practitioners (instrument nurses) participating in AC. Three themes emerged. Firstly, nurses had to negotiate the technical aspects of their duties while reassuring their conscious patient. Secondly, a controlled operative situation was considered crucial, incorporating minimisation of organisational problems and restricting communication to avert patient anxiety. Thirdly, AC was described to have a profound emotional effect, especially during cortical mapping phases where nurses felt compelled to act as intermediaries between neurosurgeon and patient. This created a nurse-patient relationship during the intraoperative period.

While findings are informative and show progress in the area, methodological constraints reduce research credibility. Conducting interviews pre and post-surgery potentially created an imbalance in reported experience where less information was

shared during the preoperative interviews (Palese et al., 2008; Khu et al., 2010). Another drawback was that direct questions used in structured interviews may have constrained answers, limiting the richness of data collected (Khu et al., 2010; Manchella et al., 2011). Involving an instrument nurse with previous AC experience in the data analysis may have biased findings of Palese and Infanti (2006). In the study of Fletcher et al. (2012) four patients declined to take part although reasons for study refusal were not documented. Moreover, the accuracy of reported experiences may have been confounded as data collection occurred between five months and four years following the AC. Finally, clinical differences are likely given four of the studies were conducted abroad and conclusions may not be applicable to UK populations.

Despite these limitations, it emerges that a good patient-neurosurgeon relationship appears essential to ensure a positive AC experience. However, given the different surgery stages (preoperative, intraoperative and postoperative), patients may have differing, phase specific interactions with all neurosurgical team members (Palese & Infanti, 2006). Therefore, other relationships could influence their AC experience. With an increase in the use of AC, investigation surrounding the influence of patientneurosurgical relationships at all operative stages is needed (Leinonen, Leino-Kilpi, & Jouko, 1996; Axelrod & DorrGoold, 2000). Such research could enhance perioperative relationship development between patients and various relevant professionals to promote trust and confidence. If the neurosurgical team do not have the skills to build such relationships, evidence indicates patient apprehension prior to and during the AC may increase (Lepola, Taljamo, Aho, & Louet, 2001).

Good patient-practitioner relationships remain difficult to define, although both parties acknowledge their value and are upset when they break down (Smith, Buss, Giansiracusa, & Black, 2007). Patient perceptions of trust, empathy and appropriate communication appear idiosyncratic (Janssen & MacLeod, 2010), evidencing optimal care as being subjective and problematic to teach (Janssen, MacLeod, & Walker, 2008). Moreover, within cancer populations, patients report difficulty in understanding practitioners and expressing feelings while practitioners underestimate communication problems and patient distress levels (Goldstein & Goedhart, 1973).

Despite recognising the importance of patient-practitioner relationships in enhancing the AC experience, an extensive literature search failed to illuminate how such relationships are formed in any 'awake' surgical procedures. Nevertheless, insight is provided through exploration of patient-practitioner interactions in cancer literature, which places emphasis on clinical communication.

Clinical communication appears to contribute significantly to the building and maintenance of patient-practitioner relationships. (Janssen & MacLeod, 2010). It is considered to underpin trust and empathy, generating future hope while creating a sense of patient morale (Street, Makoul, Arora, & Epstein, 2009). Good communication is reported to improve treatment adherence and affect clinical outcomes (Epstein & Street, 2007). McWilliam, Brown and Stewart (2000) reported how an accurate timely diagnosis and communication of information, based on need, appeared crucial for relationship development. More recently, Janssen and MacLeod (2010) concluded that practitioners nurtured caring relationships when they shaped their expression style according to their patients' preferences. Unfortunately, both studies ignored the practitioners' perspective on aspects of communication during provision of cancer treatment. Therefore, Salmon, Mendick and Young (2011) studied both patient and surgeon perspectives of communication during a consultation surrounding cancer treatment. Patients ascribed importance to the surgeon revealing their personal character. Surgeons also recognised the value of being themselves, but reported limits to being authentically natural as sometimes they considered it important not to show their character or emotions. Perhaps surgeons needed to preserve a degree of professional

detachment to ensure effective decision making (Ray, Fisher, & Wisniewski, 1986). Overall, within wider cancer contexts, relationship development appears enhanced by sensitivity to patients' informational needs and recognition of their individuality.

In summary, patient experiences of AC appear intrinsically individual and complex. They are influenced by the patient-neurosurgeon relationship (Fletcher et al., 2012) and most likely, patient-neurosurgical team member relationships (Palese & Infanti, 2006). Wider cancer literature suggests that positive relationship development is facilitated when practitioners adapt to their patients' idiosyncratic needs by adjusting their communication style. Assessing patients' desire for information throughout their illness and treatment seems particularly important (McWilliam et al., 2000), consistent with the reduction of apprehension and feelings of uncertainty reported in AC research (Khu et al., 2010; Manchella et al., 2011; Fletcher et al., 2012). The different stages of AC (preoperative, intraoperative and postoperative) may mean patients require alternative, contextually suitable behaviours from neurosurgical team members in order to feel cared for. Therefore, patient experiences of interactions with their neurosurgical team throughout the perioperative AC context may inform how positive relationships are created, enhanced and maintained. However, Salmon et al. (2011) states 'onedimensional' views surrounding relationships are incomplete and potentially misleading. Accordingly, examination of practitioner perspectives regarding relationships also seems crucial, particularly given the complex emotional task of communicating effectively with awake patients while simultaneously negotiating technical aspects of surgery (Palese & Infanti, 2006). Furthermore, research and guidelines place pressure on upcoming and practicing neurosurgical team members to use appropriate communication skills (Royal College of Surgeons, 2002). Neurosurgeons believe they require specific training to improve their ability to

communicate (Yule, Flin, Paterson-Brown, & Maran, 2006), with many lacking confidence in determining patients' information and support needs (Ray et al., 1986).

The current retrospective exploratory study employed an IPA approach and examined patient-neurosurgical team inter-relationships with particular emphasis on aspects of communication throughout the perioperative AC period (preoperative, intraoperative, and postoperative). The study aimed to investigate the lived experience of AC and perioperative interactions for both patients and neurosurgical team members. The following research questions were identified:

- 1. To explore the lived experience of patients throughout the preoperative, intraoperative and postoperative stages of AC.
- 2. To explore the lived experience of neurosurgical team members throughout the preoperative, intraoperative and postoperative stages of AC.
- 3. To explore the lived experience of patient-neurosurgical team communication for patients throughout the preoperative, intraoperative and postoperative stages of AC.
- 4. To explore the lived experience of patient-neurosurgical team communication for neurosurgical team members throughout the preoperative, intraoperative and postoperative stages of AC.

It was envisaged this would enable greater understanding surrounding effective communication approaches, thereby assisting in developing helpful patientneurosurgical team member relationships. It was hoped findings would inform education, thereby enhancing clinical outcomes and overall AC experience.
Method

Participants

Participants were recruited into two groups:

Patient Group

Multicentre recruitment occurred from two Neurosurgery Departments in the north of England between October 2013 and March 2014. Eight patients agreed to participate and were interviewed. Patients were included if they had undergone an AC procedure within the last two years, were over 18 years of age and had capacity to consent. All patients had a histology confirmed tumour diagnosis. Given the interviewbased approach of data collection, patients were excluded if they did not speak English, had significant expressive or receptive language difficulties or had a serious disabling mental health condition which they felt would influence their ability to discuss AC experiences. To avoid data complexity and the potential introduction of bias, no other exclusion criteria were set. It was felt that data saturation was reached with eight patients. Table 1 outlines the patients' self-reported demographic information, histology confirmed diagnoses and time passed since AC. The main cognitive difficulties identified following AC were surrounding memory (N=5), word finding (N=2), processing speed (N=2), and attention (N=1). Family support levels were quantified into high (N=5), medium (N=2) and low (N=1) domains based on patients' descriptions. Scores obtained from the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) revealed that most patients had no incidence of depression (N=6) or anxiety (N=7). A minority reported mild (N=1) and severe depression (N=1) or mild

anxiety (N=1). Six patients underwent AC using the 'awake' anaesthetic protocol, with two experiencing the 'asleep-awake-asleep' technique.

Participant	Pseudonym	Age	Gender	Tumour Grade	Self-reported tumour	Histology confirmed tumour	Time since awake
Number					location	diagnosis	craniotomy
							(months)
P1	'John'	42	М	II	Right motor strip, frontal	Glioma	18
P2	'Mary'	40	F	II	Front	Oligodendroglioma	9
P3	'Joan'	77	F	IV	Left side	Glioblastoma multiforme	13
P4	'Jane'	45	F	IV	Left frontal	Glioblastoma multiforme	24
P5	'Elaine'	80	F	Ι	Left posterior frontal	Meningioma	24
P6	'Tess'	58	F	III	Right motor strip	Oligodendroglioma	24
P7	'Ryan'	30	М	II	Back	Astrocytoma	13
P8	'Andrew'	42	Μ	ΙΙ	Front left	Oligodendroglioma	24

Table 1. Patients self-reported demographic information, histology confirmed tumour diagnosis and time passed since AC.

Multicentre recruitment occurred from eight Neurosurgery Departments in the UK between October 2013 and March 2014. Eight neurosurgical team members agreed to participate and were interviewed. Team members were included if they had direct patient contact throughout any perioperative AC procedure and capacity to consent. Considering the exploratory nature of the study, no selection criteria was employed for number of years in practice. It was felt that data saturation was reached with eight participants. Table 2 outlines the team members' demographic details. All reported undergoing at least one formal communication training course (range 1 to 3 courses).

Participant	Pseudonym	Age	Gender	Profession	Time since	Time
Number					qualification	involved in
					(years)	awake
						craniotomy
						procedure
						(years)
N1	'Gill'	36	F	Speech	5	2
				Therapist		
N2	'Chris'	47	М	Consultant	8	6
				Neurosurgeon		
N3	'Mark'	40	М	Consultant	4	7
				Neurosurgeon		
N4	'Joyce'	42	F	Clinical	12	2
				Neuropsychologist		
N5	'Derick'	55	М	Consultant	33	3
				Neurosurgeon		
N6	'Daniel'	43	М	Consultant	10	3
				Neurosurgeon		
N7	'Brian'	53	М	Consultant	29	7
				Neurosurgeon		
N8	'Julie'	35	F	Clinical	7	3
				Neuropsychologist		

Table 2. Neurosurgical team members' self-reported demographic information and
 length of involvement in AC procedure.

Design

The study utilised a qualitative methodological design which employed semistructured interviews. Data was examined using IPA (Smith, Flowers, & Larkin, 2009), which aims to explore and interpret how individuals make sense of their lived experience. IPA is often employed within health psychology (Brocki & Wearden, 2004) and has been used effectively in examining patient experiences of AC (Fletcher et al., 2012). Therefore, IPA was considered appropriate for investigating the processes surrounding how patients and neurosurgical team members experience and make sense of AC and their perioperative interactions. Other methods of qualitative inquiry were also examined for appropriateness prior to the section of IPA (see Appendix S for Epistemology Statement).

Procedure

Patient Group

Ethical approval was secured by the London-Hampstead Ethics Committee (see Appendix F) and site approval was obtained from two hospital trusts (see Appendix G and H). Patients meeting study inclusion criteria were identified by suitable members of the clinical team who subsequently provided patient contact details. Thereafter, patients were approached by post through a letter of invitation (see Appendix I) and participant information sheet (see Appendix J). Overall, 24 patients were contacted, 19 and 5 from the two Neurosurgical Departments respectively. Willing patients contacted the researcher directly and a face to face meeting was arranged either at the university or the participant's home, depending on convenience. Initially, the researcher offered opportunity for the patient to ask any questions. Thereafter, ethical and research issues were discussed, including confidentially, right to withdraw, participant anonymity, data storage and potential usage of interview quotes. Subsequently, the researcher obtained written informed consent (see Appendix R) and the demographic questionnaire (see Appendix K) was completed with the patient. The HADS (Zigmond & Snaith, 1983) (see Appendix L) was also administered to assess patients' mental state. The HADS was specifically chosen because of its stable factor structure, high internal consistency for both subscales, and previous recommendations for usage in studies of emotional disturbance in cancer patients (Moorey et al., 1991). HADS scores enabled contextualisation of patient narratives thereby allowing discussion of any potential bias introduced by their mental state. This was followed by a semi-structured interview lasting on average 53 minutes (range 34 to 85 minutes). Interviews were audio-recorded using a Dictaphone. After interview, patients were provided with a stamped-addressed envelope to write any further relevant information recalled following the interview.

A semi-structured interview schedule (see Appendix M) guided exploration of patients' AC experiences and perioperative interactions. The schedule included an introductory statement and 12 open-ended questions with occasional prompts. The interview structure following a temporal sequence examining preoperative, intraoperative and postoperative phases. This arrangement is alluded to in previous studies (Palese et al., 2008; Khu et al., 2010; Manchella et al., 2010) and was felt useful as a guiding framework. Further interview schedule development involved consulting two members of the direct clinical care team with AC experience. Feedback was also obtained from a patient who had previously undergone an AC. Opinions regarding the wording and order of questions were gathered and subsequent modifications were made. Thereafter, clinicians and patient felt questions were phrased and organised appropriately. Questions were not directly referred to during interviews thereby

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reducing likelihood of the researcher's AC knowledge confounding participants' narrative. Consequently, patients were facilitated in providing detailed accounts in their words and setting discussion parameters.

Neurosurgical Team Member Group

Neurosurgical team members meeting study inclusion criteria were identified through supervision groups and liaising with departmental secretaries. Contact details were obtained directly from interested team members, departmental secretaries or through departmental websites. Potential team members were approached by post through a letter of invitation (see Appendix N) and participant information sheet (see Appendix O). Overall, 37 neurosurgical team members were contacted. Willing team members contacted the researcher directly and a face to face meeting was arranged at the hospital where the practitioner worked. Initially, the researcher offered opportunity for the team member to ask any questions. Thereafter, ethical and research issues were discussed, including confidentially, right to withdraw, participant anonymity, data storage and potential usage of interview quotes. Subsequently, the researcher obtained written informed consent (see Appendix R) and the demographic questionnaire (see Appendix P) was completed with the team member. This was followed by a semistructured interview lasting on average 41 minutes (range 22 to 65 minutes). Interviews were audio-recorded using a Dictaphone. After interview completion, team members were provided with a stamped-addressed envelope to write any further relevant information recalled following the interview.

A semi-structured interview schedule (see Appendix Q) guided exploration of team members' AC experiences and perioperative interactions. The schedule included an introductory statement and 12 open-ended questions with occasional prompts. The interview structure following a temporal sequence examining preoperative, intraoperative and postoperative phases. This arrangement is alluded to in previous studies (Palese et al., 2008; Khu et al., 2010; Manchella et al., 2010) and was felt useful as a guiding framework. Further interview schedule development involved consulting two members of the direct clinical care team with AC experience. Opinions regarding the wording and order of questions were gathered and subsequent modifications were made. In addition, two questions were suggested and added regarding how neurosurgical team members believed patients experienced the AC procedure. Ascertaining team members understanding of how patients experience AC seemed important as such knowledge is likely to affect how clinicians communicate and perform operative duties (Palese & Infanti, 2006). Questions were not directly referred to during interviews thereby reducing likelihood of the researcher's AC knowledge confounding team members' narrative. Consequently, team members were facilitated in providing detailed accounts in their words and setting discussion parameters.

Data Analysis

Audio-recorded interviews were transcribed verbatim and analysed using IPA methodology described by Smith et al. (2009). Interview transcripts were interpreted on a case-by-case basis, thus following an idiographic approach. Although the researcher alternated sequentially between the two groups during data analysis (i.e., P1, N1, P2, N2) to allow greater focus of patient-neurosurgical team interactions, each group was initially analysed separately in accordance with the recommendations of Larkin, Shaw and Flowers (in development) for two group IPA analysis. Thereafter, a comparative synergy of findings from both groups is presented only in the discussion.

For each participant, interview transcripts were read and re-read, noting down descriptive, linguistic and conceptual comments in the right margin. This allowed reflexive engagement with the data. Thereafter, emerging theme titles, that is, key words that captured the essential quality of the text, were documented in the left margin. Subsequently, themes were clustered by mapping interrelations and connections. Associated excerpts to support themes were identified, ensuring analysis was grounded in the data. This process was repeated for each transcript. Following analysis of individual transcripts, within each group, themes and associated quotations across cases were collated, organised and combined. Consequently, subordinate themes were identified, being representative of all experiences for each group. Then, narratives for each subordinate theme with supporting citations were established. Associations between subordinate themes lead to establishment of super-ordinate themes. Subordinate and super-ordinate themes were not selected based on prevalence but in relation to richness of accounts, thereby adhering to the IPA approach (see Appendix T and Appendix U for a worked example of IPA analysis for patient and neurosurgical team member groups respectively).

Quality and Validity

To ensure credibility, Yardley's (2000) quality and validity assurance indicators were followed closely. In addition, the second author monitored the analytic process from initial individual analysis through to the final analysis across interviews. Thus, where any questions arose regarding the categorisation of themes, discussion ensued until consensus was reached. Transparency was certified through clearly defined research stages and recording researcher assumptions about the topic prior to study commencement. To establish internal coherence and participant validation, the researcher obtained participants' permission to contact them after data analysis to ascertain whether experiences were well represented. Furthermore, an IPA group of four researchers familiar with data analysis examined the credibility of themes and interpretations. Central to theme validation was making sure that interpretations were grounded in the data through support of participants' verbatim.

Results

Data analysis revealed four superordinate and six subordinate themes within the Patient Group and three superordinate and seven subordinate themes for the Neurosurgical Team Member Group. Findings from each group are presented in Tables 3 and 4 respectively. **Table 3.** Patient Group Superordinate and Subordinate Themes

Table 4. Neurosurgical Team Group Superordinate and SubordinateThemes

Treatment	Superordinate	Subordinate Themes	Treatment	Superordinate	Subordinate Themes
Phase	Inemes		Phase	1 hemes	
Preoperative	 "Get rid of it" "You just get 	1.1. "Oh my god, I've got a brain tumour"1.2. "Whatever's best I'll do"	Preoperative	1. "Fully in Control"	1.1 'The best option'1.2. "Making sure they're very well prepared"
Intuo on onotivo	on with it"	2.1 "It's not a natural place to	Intropportivo	2 "The conductor of	2.1. Everyone plays their
Intraoperative	of it?	3.1. It's not a natural place to be"3.2. 'What's my role?'	Intraoperative	2. "The conductor of the orchestra"	2.1. Everyone plays then part'2.2. "There are things that you can't really control"2.3. "Someone they know"
Postoperative	4. "You start to realise what you've been through"	4.1. "You've got to fight through this"4.2. "Learning to manage"	Postoperative	3. 'Recovery'	3.1. "Straightforward physical recoveries"3.2. "They often come down with a big bang"

Preoperative

Patient Group

Patient Superordinate Theme 1: "Get rid of it"

This superordinate theme captured how patients felt powerless following their BT diagnosis. The BT was often referred to as 'it'; enabling emotional distancing from an overwhelming diagnosis. However, patients also referred directly to the BT to convey feelings of shock and hatred. Overall, it appeared important for patients to express how the tumour had taken control of their lives. Patients' sense of powerlessness extended to their decision regarding AC treatment. Consequently, the neurosurgical team's expertise was utilised for emotional containment. Two subordinate themes represented these elements: "*Oh my god, I've got a brain tumour*" and "*Whatever's best I'll do*".

Patient Subordinate Theme 1.1: "Oh my god, I've got a brain tumour"

Prior to BT diagnosis, most patients believed they were healthy and seemed unaware of anything being wrong. Most described feelings of shock on discovering they had a BT. John, Jane, Mary, Elaine and Andrew reported suddenly experiencing a seizure, resulting in a hospital admission, which subsequently revealed a tumour through medical investigation. This was felt to be a bizarre situation where patients felt powerless, finding it difficult to contemplate such rapid events: "It's very strange because you're suddenly put into a scenario, having several weeks earlier being completely fit and well, then you're told that effectively you've got a brain tumour, there's every chance it could be cancerous but, you know, I mean, the word brain tumour, just, you know, instantly I think most people think, 'oh my god, I've got a brain tumour', you know, 'how long have I got left' type of thing" John (Page 3, Lines 9-15)

"I'd had nothing wrong with me prior to suddenly having this huge seizure. Um, so then it was like, well I suddenly saw the world of the neurosurgical team" Andrew (Page 3, Lines 41-44)

It seemed Ryan's feelings of shock were exacerbated by how his tumour diagnosis was communicated. Following an eight month period of epilepsy, he described being told abruptly about his diagnosis:

"I went in and he said 'you've got a grade two tumour'. And I went, 'have I?' And they went, 'Yeah. Didn't you know?' I went 'No'" Ryan (Page 2, Lines 49-50 to Page 3, Line 1)

Tess explained being aware of her tumour for several years and had been adopting a 'wait and see' approach. Following the initial diagnosis, she described hatred towards her tumour due to the level of control it exerted and uncertainty regarding whether it would grow:

"I hated having...the thought of having a tumour in my head all those years" Tess (Page 2, Lines 6-7)

Jane and Mary further described how events surrounding the diagnosis impacted others around them:

"I hadn't really been having um, many symptoms before the full seizure, um, so it was a real shock to both myself and for my husband" Jane (Page 3, Lines 1-3)

"I think it, obviously worse for him (husband) than it was for me because I don't remember any of it" Mary (Page 2, Lines 30-31)

During this time, most patients described difficulty in remembering information presented to them by the neurosurgical team due to being in shock or because of cognitive deficits. Patients emphasised the perceived helplessness of their situation when stating they were "not long for this world". Consequently, they desired to "get rid of it" but seemed uncertain regarding how their situation could be resolved.

Patient Subordinate Theme 1.2: "Whatever's best I'll do"

Feelings of shock and powerlessness surrounded the patients' bizarre situation, compelling an attachment to the neurosurgical team by placing complete trust in them. Patients were comforted and reassured by their team's expertise, which enabled development of a trusting relationship. This allowed some containment of overwhelming feelings. It seemed relying on the team was essential for patients to develop any hope of *"getting rid of it"*:

"They said do you want this or do you want this and I said 'you tell me what the best thing is because that's what I want'" Joan (Page 2, Lines 35-36)

"I think I just felt trust. I think I just felt this guy has had a bit of training. It sounded like he knew exactly what's he's talking about and uh, clearly he does know what he's talking about because I'm still sat here today" Andrew (Page 4, Lines 41-44)

Patients reported that trusting their neurosurgical team resulted in them being directed towards AC treatment. The concept of 'awake' brain surgery was met with idiosyncratic reactions. John and Jane found AC a bizarre notion; expressing shock and disbelief regarding it being physically possible, as highlighted through their laughter:

"I did turn round to my neurosurgeon and asked him whether that was physically possible because I didn't believe that you could operate on somebody's brain while they're awake (*laughs), it clearly just didn't make sense to me" John (Page 1, Line 50 to Page 2, Lines 1-4)

"I was slightly in shock because I'd never heard of an awake craniotomy before and one of my friends had, well I thought she was joking when she said, 'are you going to be awake during the operation?' But then I found out that she was right (*laugh), um, so (*laughs), that was a bit of a shock" Jane (Page 3, Lines 26-30) Ryan reported feeling worried about being 'awake' and wondered if he would experience pain:

"The awake bit was a bit worrying, but the doctors reassured me and said, you won't feel a thing" Ryan (Page 2, Lines 14-16)

In contrast, Joan did not seem concerned by the operation and Tess reported feeling relieved due to a fear of general anaesthetics:

"It didn't worry me one little bit when they said awake" Joan (Page 3, Lines 46-47)

"I thought that was marvellous because I'm terrified at general anaesthetics (*laughs)" Tess (Page 2, Lines 3-5)

Regardless of reactions, it seemed patients felt an expectation or pressure to choose the option of AC and behave appropriately thereafter to assist the team:

"He just tells you it was right...the right thing to do" Tess (Page 2, Lines 24-25)

"Well at the time you just sort of go along with it don't you I think, I think it I thought it was a really bad idea, but everybody was you know, this is what's going to happen" Mary (Page 3, Lines 5-7) Patients' accounts also highlighted how the BT exerted tremendous control over their decision to undergo an AC. Although different treatment options were available, John, Mary, Joan and Andrew described how the tumour's position and a sense of treatment urgency left them in a powerless position whereby AC appeared the only rational and safe choice:

"it was quite an easy decision because if someone says to you, you know, you're 99.9 percent likely to be paralysed if we put you to sleep and if we don't, you're likely to be, there's a risk of having some weakness or some light paralysis, but probably that will then recover, it's not really a very hard decision to make" John (Page 2, Lines 41-46)

"When they said I wouldn't be able to speak if they did it the other way round it wasn't really another option, so yeah, you know, I just went along with it" Mary (Page 3, Lines 39-41)

"I'd been given the three days to make the decision, um, but what I told her then was that it was a no brainer (*laughs), my sense of humour" Jane (Page 3, Lines 33-35)

Patient Superordinate Theme 2: "You just get on with it"

Although patients experienced feelings of helplessness regarding their situation and impending surgery, it was understood that they tried to obtain a sense of control by "*get(ting) on with it*". Their psychological reactions towards the diagnosis, concept of 'awake' surgery or procedural risks, motivated usage of idiosyncratic strategies, which could be considered defence mechanisms, to enable emotional containment. It appeared the common aim of patients' individualistic strategies was to optimise team performance through becoming their perception of a 'helpful' patient. John best highlighted the importance of obtaining a degree of control:

"Ever since the day I found out I had a tumour, I was just like, let's move forward, let's find out how we resolve it and there is no other option" John (Page 6, Lines 10-11)

Mary acknowledged how patients might require different strategies whilst placing responsibility on the neurosurgical team to identify how patients best prepare for surgery:

"Yeah, they were good for me but whether they'd be good for other people who want more information, I suppose that's what they're trained, aren't they, to do aren't they, they're trained to sort of work out how you want to be treated" Mary (Page 11, Lines 41-45)

Patients' main approach towards emotional containment and surgery preparation related to the amount of information received. John, Jane, Elaine, Andrew and Ryan actively sought information about the AC procedure to feel prepared. Tess emphasised how it was important for information to be paced appropriately and tailored based on her preferences. It appeared information provided reassurance regarding the operation:

"Having it described step by step helped me feel as though I would be able to get through it" Jane (Page 2, Lines 37-39) "He spoke to me and um...explained everything, thoroughly...as thoroughly as I wanted anyway" Tess (Page 2, Lines 21-23)

In contrast, Mary made a conscious effort to avoid information about the AC as she believed it would have caused increased anxiety. To prepare for surgery, she placed her complete trust purposefully in the neurosurgical team's expertise which alleviated some of the emotional intensity experienced surrounding the approaching procedure. Therefore, Mary's relationship with the team was utilised as an extension of strategies to enable emotional containment:

"I didn't really need a huge amount of information really, it was just what was going to happen so you just get on with it don't you? I'm not the kind of person that needs it all in, because at the time there was that programme of television, it was all about, um, awake craniotomies wasn't it and they were showing them on television and people kept saying, 'oh, have you watched it?' And I said no, I think I'll, I'll pass on that (*laughs) until it's all over and done with" Mary (Page 4, Lines 32-40)

However, on the day of the operation, Mary expressed a desire for certain information surrounding the procedure. Therefore, it appeared she wanted information to feel prepared, but importance was placed on a timely delivery:

"It wasn't until the day of the operation that, when I asked, and they said, oh yes, you can have a bit of something to relax you', so that was the only thing in the whole time that did panic me slightly" Mary (Page 3, Lines 31-34)

Patients adopted a range of approaches to cope with emotions and prepare themselves for surgery including avoidance or distraction, stoicism and humour. Given most strategies occurred within the context of the neurosurgical team, controlling emotion may have been a combination of patients' self-imposed approaches and the neurosurgical team strategically adopting or building upon patient coping mechanisms:

"I was just like right, clench your teeth, just get it done" John (Page 7, Lines 12-13)

"...and (speech and language therapist) was making jokes, like you know, 'do you know you can have a picture of your brain?' And pictures of before and after, which I've got in an email somewhere (*chuckles). So, she just made you laugh. And then, that was it really...like just...just made you feel at ease" Ryan (Page 3, Lines 46-49 to Page 4, Lines 1-3)

Neurosurgical Team Member Group

Team Superordinate Theme 1: "Fully in Control"

This superordinate theme captured how team members felt it imperative to be *"fully in control"*, facilitated by a team experienced with the surgical procedure and preparatory elements as defined by the neurosurgeons' preferences. It appeared the neurosurgical team exerted significant influence over patients' decision to undergo AC,

confining their approach to only those perceived as 'appropriate'. Preparing 'suitable' patients for their operation seemed paramount for optimising intraoperative cooperation, and accordingly, the effectiveness of surgery. This *"work-up"* strategy seemed enhanced by communication of information and building of familiar relationships. Being in *"control"* was felt to be synonymous with safety, ensuring all possible eventualities were accounted for and minimised where aversive:

"I see my role as, one, deciding if I think that awake craniotomy is appropriate, although we usually discuss, we usually discuss that at the MDT beforehand, two, for surgical planning, deciding where we're doing things" Chris (Page 4, Lines 2-5)

"There's a team of people around them who are fully in control to make sure they're comfortable" Derick (Page 3, Lines 30-31)

Patient anxiety was considered the most concerning threat to safety during the procedure. Therefore, a predominant preoperative tactic emerged focused on managing and containing a patient's adverse emotions in order to remain *"fully in control"* throughout:

"The critical thing is trying to reduce the anxiety level down to as low as possible. Because anxiety causes problems in the operating room" Derick (Page 3, Lines 21-23)

"...anxiety increases their blood pressure, raises their pulse, and you, you fight the battle from the start" Daniel (Page 3, Lines 45-46)

Two subordinate themes represented these elements: *"The best option"* and *"Making sure they're very well prepared"*.

Team Subordinate Theme 1.1: 'The best option'

Team members considered AC as *'the best option'* to safely remove the BT given the patients' mode of presentation. It was felt that proceeding with this decision would alleviate anxieties within the neurosurgical team regarding the likelihood of causing harm, thereby optimising advantage for the patient:

"...it's a benefit to me a little bit because it makes me more relaxed about what we could do for the patient" Daniel (Page 7, Lines 8-10)

"...it makes so much safer for us" Brian (Page 2, Line 46)

Accordingly, Gill, Mark, Joyce and Daniel explained how being perceived as an 'expert' exerted significant *"control"* over a patient's decision to undergo AC. This proficient position may have been utilised advantageously by the neurosurgical team, perhaps persuading patients to choose AC over other options, given their opinion that it was *"safer"*.

"Well, I don't generally give them a choice. I say that if we want to maximise extensive resection and minimise post-operative deficit, if I do it with them asleep, I won't be able to achieve the same result. And therefore, that will adversely affect their outcome, their prognosis, their long-term prognosis, survival etcetera, etcetera. So, I say to them we need to ... I say 'we need to do this. If we're going to do surgery, we need to do this with you awake.' And so, I state that this is a fact, not an option" Mark (Page 2, Lines 24-32)

"I'm not sure that they (patients) necessarily feel that they're making much of a decision. They are following the advice that they are being given" Joyce (Page 4, Lines 47-50)

"The person's decision to engage is based on the neurosurgeon's opinion, but that in itself is sound" Julie (Page 3, Lines 37-39)

Derick and Daniel emphasised that they would only operate if they were satisfied their patients had chosen to proceed as a collaborative agreement, having fully understood what was going to happen. In contrast, Gill and Joyce were concerned over whether patients' circumstances and understanding allowed them to make an informed consent, especially given the urgency of treatment. Consequently, the level of choice patients exerted over their decision to undergo AC remained unclear:

"...there is an issue of consent, but generally speaking, I think, for the patients, where it's, 'we need you to come in, we need to do this quickly', so, they'll say, 'okay'" Joyce (Page 5, Lines 1-3)

"It's done by a mutual agreement between myself and the patient. So I basically explain to them the logic as I said of why we want to do it. And

only when the patients have satisfied me that they fully understand what's going on and then agree to it, will I go ahead" Derick (Page 3, Lines 6-10)

Although team members presented AC as *'the best option'*, selection appeared exclusive to only those patients considered *"suitable"* by the neurosurgeon. Predefined specific criteria were applied to identify candidates believed to able to *"cope"* with the procedure. 'Coping' was iterated as a patient's ability to manage their emotional reactions within an unusual environment, ensuring their ability to cooperate fully with the neurosurgical team, thereby allowing maintenance of *"control"*:

"Not all patients can cope with the idea and that's another thing. It's something I explore in clinic" Chris (Page 1, Lines 39-40)

"My finding is that there's not that many patients who I think fulfil my criteria" Daniel (Page 6, Lines 5-6)

"I think we make a judgement very early on whether a patient is going to be suitable for an awake, because not everybody is" Brian (Page 1, Lines 27-29)

Despite team members' universal agreement that 'suitability' was paramount, disparate criteria were employed when selecting patients. Chris considered patients who consistently avoided information surrounding AC would be unable to cope when faced directly with an operating environment. Mark described how patients who presented with anxiety tended to cope better during the operation, whilst those with a *"blasé"* attitude capitulated. In contrast, Daniel considered avoiding introducing the concept of

AC when patients appeared unduly anxious, utilising "*nonverbal communication*" to identify potential indicators. He believed older, male patients were most suitable as they often presented with less anxiety. Although Brian concurred with Daniel's view that a nervous disposition was disadvantageous, he thought women coped better than men throughout the perioperative period:

"I've had patients who will not look at their scans, who don't want to know anything about what's going on. Those sorts of people I don't believe will be able to cope with waking up in the middle of an operation" Chris (Page 2, Lines 5-8)

"...sometimes the ones who are most anxious, actually do the best when you wake them up. Because they're sort of worried about it and, it seems, to cope better once they wake up for some reason. Those who are very blasé and not thinking about it, when they wake up, tend to...I think because they've not thought about it, they might not be as well-prepared or have thought what to expect" Mark (Page 2, Lines 43-49)

"...my favourite patients are sort of late middle aged to elderly, male, thin patients. They just seem to be not quite so anxious about the idea and be a bit more sanguine and relaxed about it. Uhm, so, if we, if I, when I, when ...a lot of it's about the nonverbal communication. So, if the patient looks particularly anxious then, you know, I might, I might decide, well, perhaps, you know, this person, I'm not going to even approach the issue" Daniel (Page 1, Lines 43-49 to Page 2, Line 1) "If you're very nervous, if you just have the wrong disposition, we quite quickly make a judgement. We are dealing with a fairly young population, in their 30s and 40s, 20s to 40s usually. The women are much better at coping with this than the men throughout the whole process" Brian (Page 1, Lines 29-34)

The diverse selection criteria for *"suitable"* patients were characterised from the neurosurgeon's experiences with the procedure, and accordingly, were based on personal preference. Despite their subjective selection process, Chris and Daniel acknowledged a lack of objective criteria:

"...we're unsure about indications for awake cranies at the moment" Chris (Page 2, Lines 2-3)

"...we would certainly make a very, you know, not objective but subjective assessment of the patient about their suitability" Daniel (Page 2, Lines 13-14)

Team Subordinate Theme 1.2: "Making sure they're very well prepared"

Team members seemed eager to emphasise the importance of preparing patients for their impending surgery. It appeared imperative to ensure patients had a *"full understanding"* of the procedure and what was expected of them throughout surgery. This was believed to reduce anxiety and patient cooperation both before and during AC, thereby maintaining *"control"*. Without appropriate *"pre-operative work-up"*, team members considered operative success and effectiveness would be severely compromised:

"...a lot of time spent, prior, within the neuro-psychology sessions, is actually informing them (patients), making sure they're very well prepared" Joyce (Page 1, Lines 28-30)

"I then go on to explain that to be able to do one of these procedures properly, we require their (patients) full understanding and complete cooperation" Derick (Page 1, Lines 37-40)

Julie explained how informing patients of their intraoperative requirements was a tentative process, as they might feel pressurised about performing optimally. Accordingly, there seemed potential for patients' anxiety levels to be raised if they interpreted that AC success would rely solely on their ability to cooperate:

"It is really important to prepare them very well and that increases the chances of success for them. But, also kind of helping them to understand what's expected of them, but not to overwhelm them so that they're going to be in a massive panic" Julie (Page 2, Lines 14-18)

However, the amount of information offered to patients varied amongst team members. Gill and Derick only provided patients with a broad overview of operative elements whilst Joyce preferred to report chronologically specific details surrounding the procedure: "I explain in overview, not much detail" Derick (Page 1, Line 29)

"...go through it with them step by step" Joyce (Page 2, Line 30)

Although the amount of information offered to patients appeared diverse, often utilising medical language and terminology, its content covered similar themes across team member accounts. These were: a rationale for pursing AC, a description of the operating environment, an emphasis on the usage of local anaesthetic to alleviate pain, the possibility of unpleasant operative events, encouragement to communicate any intraoperative concerns, the rehearsal of any likely intraoperative speech or motor tasks, and an emphasis on the real possibility of postoperative deficits:

"...explaining in detail why they need to be awake in having their craniotomy; the anatomical and physiological basis for that advice" Derick (Page 1, Lines 27-29)

"I discuss with the patient about how you will be lying and what you will be able to see when you wake up and what it's going to feel like. Uhm, they meet up with the anaesthetist as well and she gives quite a lot of information about what's happening and who's going to be there" Gill (Page 4, Lines 29-34)

"...they'll be an enormous quantity of local anaesthetic into the surface of the head so that they can't feel any pain directly from what I'm doing and the inside of the head is completely pain insensitive so again, no pain" Derick (Page 2, 43-46) "...but it might be that at some point, they might stimulate the brain and you, the patient, you find that you're unable to respond in any way, not to panic about that. That's partly what we're looking for. And that just tells us very clearly that the surgeon needs to stay away from that area" Joyce (Page 3, Lines 12-17)

"...we'll be able to talk to you if there's a problem or you're sore or you're uncomfortable, you tell us and we'll do something about it" Chris (Page 2, Lines 30-32)

"...they get shown the test beforehand anyway so they know exactly what to expect. And, we're quite careful to say that it's not, you know, it's not a test as in you pass or fail but it's merely a measurement of what's happening while the language mapping is being undertaken. So, you know, it's important that you go through everything beforehand so that, you know, they can do it in the first place" Gill (Page 5, Lines 6-12)

"...when they go back onto the ward, they might get a little bit of oedema or a bit of swelling. They might find that their language deteriorates. But, they don't need to worry about that because actually, what we know, that how they are in theatre is going to be their kind of, their permanent function" Joyce (Page 3, Lines 43-48)

There was universal agreement among team members that a repeated and consistent approach to communicating preoperative information over several appointments was essential because patients were usually too anxious to retain content when first presented. This also allowed opportunity for questions, helping to provide reassurance and emotional containment:

"...in a way, we're kind of all reiterating the same message about what, what will happen, that you'll, you'll go to sleep and then you'll wake up and this will happen and, and answering the questions in the same way. So at least there's a consistent approach" Gill (Page 4, Lines 34-38)

"Most patients when you give them the information which is complex, in a stressful environment, about ninety percent goes out a window first time you speak to them which is partly why I believe in reiterating things" Derick (Page 2, Lines 17-20)

While most team members described utilising a team approach to communicate consistent information, augmented by practitioners experienced and involved with specific procedural elements, some preferred several sessions with a single team member. It was felt that preparatory protocol differed across neurosurgical departments:

"So, uhm, they will all, you know, they (team) are aware of what goes on in the procedure so they'll all be available to sort of discuss if the patient has got any particular questions" Daniel (Page 8, Lines 7-10)

"...they will be spending quite a lot of time with me; and that, this is the kind of, probably the longest part of the process. They come, they have all their appointments with me" Joyce (Page 6, Lines 21-24)

It appeared some team members preferred to offer the same information to every patient using a rehearsed *"spiel"* or structured approach. However, Daniel and Julie emphasised the importance of adapting provision of information according to their individual patient's clinical and psychological presentation:

"I suppose each person is individual as well in a sense that you might judge by someone's stress or anxiety levels, how much information they're going to need and how much you're going to have to be explicit with them about the purpose or not so explicit" Julie (Page 2, Lines 18-22)

Joyce highlighted the need to be aware of patient defence mechanisms throughout their *"preoperative work-up"* since these carried the potential to compromise scrutiny of information. Managing such defence mechanisms effectively was considered essential, thereby ensuring patients' full contemplation of the reality of their impending surgery:

"And 'she's got no concerns about surgery'. You have to be careful with that, because that's a situation where I think there's a little bit of the defensive mechanisms going on there. And she just doesn't want to think about surgery" Joyce (Page 2, Lines 1-5)

Team members described how providing information over several meetings facilitated relationship building with patients, augmenting preoperative preparation. It was felt that attachments could provide patients with a sense of 'familiarity' during the procedure, allowing emotional containment and reassurance for aversive feelings: "...they've got their friendly psychologist plus or minus a speech therapist who they've already spent some hours with who's going to be with them throughout the whole procedure. So they are basically with, at least two, at least two members of the two teams, that's the surgical team and the psychology and speech therapy team, who they have spent some, at least several hours with before the procedure, so it's not an unfamiliar group of people" Derick (Page 3, Lines 37-45)

"...they'll be a speech therapist there who you'll meet preoperatively, so there's a familiar face. And, that'll be the same person who's there during the awake craniotomy as well" Mark (Page 2, Lines 13-16)

"...one single friendly face all the way through" Daniel (Page 4, Lines 26-27)

Intraoperative

Patient Group

Patient Superordinate Theme 3: 'Making sense of it'

This superordinate theme reflected patient perceptions of the operating environment. Although diverse recollections were reported, it appeared that the majority of patients experienced vivid memories surrounding unique aspects of their AC. Being 'awake' was emphasised as an unusual event where patients struggled to 'make sense' of experiences, despite attempting to attach terms of reference, and their bewilderment remained when attempting to describe their procedure afterwards. Patients' perceptions of AC as bizarre were exacerbated by inability to fully process what was happening with pressure arising from uncertainty as how best to assist the neurosurgical team. Such experiences intensified pre-existing apprehension levels with patients attempting to manage their emotions by invoking individualistic coping strategies and containment through relationship with a key member of the neurosurgical team. Two subordinate themes, "It's not a natural place to be" and 'What's my role?' captured these elements.

Patient Subordinate Theme 3.1: "It's not a natural place to be"

Patients perceived the operating theatre as a previously unknown "*not a natural place to be*" comprising unusual equipment, noises, smells and unfamiliar people undertaking multiple tasks that resulted in them feeling overwhelmed. John, Joan and Elaine described trying to contemplate a large amount of sensory information and at

times appeared unsure about what was happening or how to '*make sense*' of it. Such experiences led them to focus attention on various aspects of the procedure, adding to feelings of apprehension:

"There's a lot of talking around you, clearly there's a huge amount of machinery and kit and whatever and as John Cleese used to say, you know, the machine that goes bleep or whatever so, as long as it keeps going bleep you're alright" John (Page 8, Lines 10-14)

"Now and again I could hear the voices and I could, at one point I heard him say, um, I heard one of them say 'oh look, there it is! Did you see it? Did you see it? There it is!' So they must have been in my brain then" Elaine (Page 3, Lines 40-44)

Patients tried to normalise the bizarre experience of being 'awake' by attaching known frames of reference to contain their apprehension. Joan and Tess both attempted to *'make sense'* of the procedure, relating previous recollections of unique medical procedures that were perceived to contained similar elements to AC. Having to resort to previous idiosyncratic events as descriptors indicated their eagerness to emphasise how difficult it was to communicate perceptions of an operation to somebody who has not been involved directly. It was felt that having an AC was such an exclusive experience that it remained difficult for patients to describe, even after the event:

"It's a bit like when I had my cataracts done. You're awake and they drive into there and then they pop into there and you're to lay there with your eyes open" Joan (Page 5, Lines 37-40) "I could remember a lot of people around me. A bit like giving birth actually" Tess (Page 3, Lines 48-49)

In order to contain and manage emotional distress associated with AC, John, Jane and Elaine attempted to normalise their experiences to make them less unpleasant by attaching a frame of reference:

"...sucking on the sponge on the end of a sausage stick is not a very pleasant experience anyway, you know, but that's something I will always remember about the operation because I always think of, kind of, you know, cheese at kids parties (*laughs)" John (Page 9, Lines 41-45)

"...when they'd put all the clips in, which did seem to take forever, I think it's because, I associated it with me using a staple gun at work, so, because that was the sound that they made as they were going in" Jane (Page 6, Lines 37-41)

"...it felt like, you know, when you go to the dentist and they're sucking, it felt like they were taking some, whatever, fluid, blood, whatever, they were sucking it" Elaine (Page 5, Lines 9-11)

The majority of patients appeared to have fragmented memories surrounding their intraoperative experiences. Accordingly, vivid remembrances surrounding predominately negative perceptions were accompanied by inability to recall other
aspects of the procedure, perhaps reflecting an attempt to negate other unpleasant experiences:

"I didn't want to hear it when they started drilling or sawing into my skull and I was terrified that I was going to hear the sort of saw and, I waited for that horrible noise to start" Tess (Page 4, Lines 13-15)

"I really can't remember apart from what I've told you" Tess (Page 6, Lines 6-7)

The use of gruesome and graphic language accentuated how patients found the procedure frightening and *"bloody horrible"*. The distressing nature of AC was highlighted particularly through Andrew's description. His stammering conveyed the emotional impact of his experiences and how attempting to recall events continued to affect him:

"They locked down my brain. They uh cut me from ear to ear uh, then they broke open my skull then they...then they um woke me up and then they um started to remove parts of my brain, the front left part of my brain. Um and then they uh put me back together again basically. They, they, they, then um put back my skull. They put some um steel in my head. I don't know if there's a nicer phrase for it!" Andrew (Page 1, Page 36-43)

John reported feeling powerless and terrified from sensory awareness of the neurosurgical team drilling into his skull, despite paradoxical absence of pain, reinforcing the bizarre nature of AC. In contrast, Ryan recalled being distressed at experiencing unexpected pain during the procedure which could be neither explained nor resolved by the neurosurgical team:

"I'm thinking, 'oh god, I know they're cutting my head open, I know they're going into my brain, I can't feel anything" John (Page 12, Lines 15-17)

"I had pain in my jaw and they couldn't explain why. Cos it was like...it must have been sucking blood out or something. And every time they used that...I got pain down the right side of my jaw. They couldn't explain that" Ryan (Page 5, Lines 4-7)

Both John and Ryan also reported anguish from visualising mentally what the neurosurgical team were doing to their brains. Ryan's account highlighted the fear invoked by thinking how close the neurosurgeon was to eloquent brain areas and the potential for damage, despite recognising the safeguard of being awake:

"You know what's going on and so you can visualise it and you just think "it's horrible" John (Page 13, Lines 11-12)

"But when he was testing around the area, I kept getting a lot of flashing. And they said, 'No that's it'. You know, because it must have been close to my nerve. So I just said, 'That's it.' At which...if I hadn't been awake, I don't think I could relate that information back to him...he wouldn't have known" Ryan (Page 5, Lines 18-23) Paradoxically, Mary and Andrew contradicted their earlier accounts regarding the distressing nature of AC by also stating that the procedure was not unpleasant. Distress arising from recall of intraoperative experiences was sometimes averted through minimising unpleasant memories. It is also possible that they felt indebted to their neurosurgical team having survived the procedure making it obligatory to avoid criticism. Alternatively, patients may simply have been recalling less upsetting elements of their AC:

"It's not an awful experience at all. I had a filling in my tooth last week and it was worse ha ha (*laughs)" Mary (Page 1, Lines 19-20)

"I didn't find anything difficult" Andrew (Page 8, Line 5)

It appeared that, for John, negative experiences of AC continued to provoke distressing emotional reactions, possibly triggered by situational cues similar to those encountered during surgery:

"Air drills! (*laughs). I went to see my dentist the other day and I was just like, obviously I had to tell him because of all the drugs that I'm on and everything else and I just said, 'look, please', you know, 'air drills are just no'" John (Page 12, Lines 46-49)

Patient Subordinate Theme 3.2: 'What's my role?'

Patients' attempts to 'make sense' of their bizarre circumstances were also challenged as they contemplated how best to assist the neurosurgical team to optimise outcome. They expressed uncertainty regarding the nature of their *'role'* in theatre, possibly contributing to feelings of apprehension. The majority described a paradox of feeling caught between 'isolation from' and 'integration within' their team. Patients often iterated fluctuating between these two roles, being unsure which was appropriate:

"I think the reality is the neurosurgical team are working as a team, they're not really, and you're not really a part of that" John (Page 11, Lines 14-15)

"There wasn't any interaction between myself and the people who were operating other than when they were putting the frame on and you know, asking if I was ready for them to do certain things" Jane (Page 8, Lines 15-18)

"Everybody sort of made me feel as though I was a part of it, I never felt as though they were doing their job and I was just there because I needed to be, it felt as though we did it together" Mary (Page 8, Lines 2-5)

"I was helping them a lot because they knew where the tumour was and they knew what to take out...But every time they took something out, they tested. So they said, 'we're going to test again'. And if I saw flashing, I'd tell him" Ryan (Page 4, Lines 43-47)

John's account emphasised his apprehension from being placed within this paradox of role uncertainty as indicated by his laughter:

"They kind of said, 'look, do you think we should stop this?' And I thought that was a question they were having between themselves, and they were actually kind of asking me (*laughs)" John (Page 8, Lines 32-34)

Patients' uncertainty surrounding their role was integrated with significant self-induced pressure to behave correctly for the neurosurgical team in the absence of clear understanding of what this constituted. Jane and Joan both placed pressure upon themselves, adopting a position of separateness until the team promoted their involvement, perceiving this would optimise performance and surgical outcome:

"I had so much faith in them and I didn't want to break their concentration so I just thought well I'll do my bit (*laughs) by staying still and such like and let them do their bit and that'll reserve my energy for, you know, sort of making my movements" Jane (Page 6, Lines 22-26)

"I know I laid still and I'd done everything that I should have" Joan (Page 1, Lines 38-39)

The magnitude of self-induced pressure was highlighted by Mary and Tess's selfblaming responses while experiencing a temporary deficit associated with cortical mapping. Despite preoperative assurances to the contrary, deficits were still attributed as a personal failure that they perceived had compromised the success of the operation. Furthermore, Andrew found this pressure overwhelming when attempting to behave 'correctly'. Feelings of anger emerged and then progressed to a state of guilt arising from a failure to contain his emotions, leading to concerns that his responses might have adversely affected the neurosurgeon: "...you knew he was going to some area he wanted to get at but obviously couldn't because, because I couldn't speak, um, so you feel like you've failed a bit (*starts crying), that he hasn't been able to get it all" Mary (Page 5, Line 50 to Page 6, Lines 1-4)

"I started effing and blinding a little bit saying 'he said this now for ... I know you said this before a few times and now you're still saying it. How long will this blinking thing go on for'? And he was doing his job and I (*laughs)...so I felt quite bad about, you know, um (*pause), saying those things to him because that, you know, he was doing the job he was supposed to do" Andrew (Page 7, Lines 37-43)

Patients adopted a range of idiosyncratic approaches in an attempt to manage emotional reactions associated with these pressures. Their predominant strategy appeared to be placement of complete faith in the expertise of the neurosurgical team. Reassurance offered by the team seemed to reinforce patients' trust, particularly during operative stages which they perceived as aversive or isolating. Ryan described how reassurance offered by his neurosurgeon contained his emotions when experiencing temporary loss of vision:

"They're always checking and (*pause), they're always reassuring me. Like when I lost that bit of vision. Mr Neurosurgeon said 'you might have lost it for now (*pauses) because of swelling'. And he told me while I lay there... 'I'm not so worried about that'" Ryan (Page 6, Lines 20-24) When feeling isolated, Mary, Tess, Elaine and Andrew explained how being informed periodically about both the operative stage and its progress was reassuring, evoking confidence that surgery was proceeding well, they were fulfilling their role adequately and that they could trust their team:

"When they were reassuring me, you know, that um, 'was I ok'? Um, but it was good that they were saying that, yeah" (Elaine, Page 5, Lines 30-32)

"I remember (neurosurgeon) talking to me from behind saying, 'it's alright, it won't be long now. It won't be long now'. I think he said that a number of times" Andrew (Page 7, Lines 34-36)

Patients also adopted other approaches to manage their emotions during surgery including reciting an internal mental checklist, avoidance or distraction techniques, stoicism and humour:

"I felt them drilling and, but that didn't alarm me because, like I said, it was just, you know, my checklist, I'd been warned about what I would hear and smell" Jane (Page 5, Lines 42-44)

"Once I heard him singing, you know, I just concentrated on that" Jane (Page 5, Lines 30-31)

"I'm quite good at putting a front on and I think what happened is, I put not just my front on but also I used all my kind of, I guess my drive, my determination, my, you know, the skills that I've built up over life" John (Page 10, Lines 46-50)

"I had a laugh with one or two of them, because one of them, his niece, it was her birthday the same day as mine" Joan (Page 4, Lines 49-50)

Perhaps the most important anchor in providing emotional containment and a sense of safety during this time was the formation of a relationship with a key person. This attachment appeared pivotal in enabling patients to make it through their surgery. The essential nature of this relationship was highlighted by John who was so eager to emphasise the strength of the emotional bond with his physiotherapist, that he stated wanting to *"marry her"*. Even discussing this relationship invoked a strong emotional reaction, stressing the magnitude and lasting nature of his gratitude towards someone so crucial in helping him through the operation:

"My physio. I'd marry her, tomorrow. Not for the normal reasons of wanting to marry someone (*chuckles), just because of the humanity, the pure baseline humanity and sensitivity and genuine compassion that helps you through the operation, and I still find that very, very emotional" John (Page 13, Lines 43-47)

"Her undivided attention was on me and I hadn't expected that. I suppose it's watching too much Holby City and Casualty (*laughs)" Jane (Page 7, Lines 42-44) "I suppose the anaesthetist, he was keeping me calm here wasn't he? Yes, he was. And I remember him going over there and I was terrified because he'd left me (*laughs). He said, 'It's alright. I'm coming back'. So I was aware of him looking after me" Tess (Page 5, Lines 35-39)

It was considered that this relationship also assisted in clarifying a patients' role, enhancing containment, whether integrated within the team or uncertain about their involvement. John, Jane and Joan described how their key team member acted as an intermediary voice, bridging them with the team, relaying any concerns and explaining how to fulfil intraoperative tasks, thereby helping to clarify their integrated role:

"The interaction is all via your physio to them" John (Page 11, Lines 30-31)

"If I had something to say, (psychologist) would have stopped them, and told them" Joan (Page 4, Lines 44-45)

In the absence of an intermediary, Elaine expressed continuing uncertainty of her integrated role, being hesitant to communicate important information to the team for fear of behaving inappropriately:

"...it was hurting and I was thinking how can I let them know, I'm thinking, yes, how can I let them know that this is really hurting and I managed to sort of squeeze my eyes a little bit so maybe they got the message that it was hurting" Elaine (Page 5, Lines 5-8)

Team Superordinate Theme 2: "The conductor of the orchestra"

This superordinate theme captured how the neurosurgeon required complete control within the theatre environment as a *"conductor"* of inter-relating operative elements. Being in control was considered synonymous with safety, facilitated through interactions with the neurosurgical team, who honoured the neurosurgeon's preferences and direction as *"the conductor of the orchestra"*:

"...(neurosurgeon) is like the conductor of the orchestra, so she will say, and then my role very much interacts with her" Julie (Page 5, Lines 14-16)

"Everybody knows where everybody is, what they're supposed to be doing and kind of work as a team" Gill (Page 6, Lines 49-50)

The presence of "*a good team*" exuded calmness within the operating environment and was believed to reassure both members of the neurosurgical team and awake patients. This relaxed setting facilitated events to proceed "*smoothly*", preserving a sense of control. Importance of "*the right personnel*" was also emphasised as team members highlighted the negative impact of having practitioners present who were unfamiliar with the neurosurgeon's preferences, procedural elements and appropriate conduct:

"...because we've been doing them a while with the same team, everyone knows what to do now, you know, it sort of runs quite smoothly and quite sleekly" Mark (Page 3, Lines 44-46)

"...knowing that we've got a good team of people around in theatre. So if there's, if there's some experienced nurses or nurses that I've, theatre nurses that I've got a lot of faith in, then that is helpful. Uhm, having my favourite anaesthetist, the favourite anaesthetist with me is, well, is not just helpful now. It's become a, you know, it's an essential" Daniel (Page 10, Lines 18-24)

"If we have people who haven't been involved in this before, it is much more difficult, as they don't understand what needs doing. So, we try to get the right personnel involved" Brian (Page 5, Lines 17-19)

Despite "preoperative work-up", the reactions of awake patients appeared unpredictable within the theatre, introducing an aspect of 'uncontrollability' to proceedings. Consequently, members of the neurosurgical team utilised their previously established patient-practitioner relationships in an attempt to contain patients emotionally and restore control. However, an important question was raised surrounding whether awake patients were part of an "orchestra", being incorporated with operative elements, part of an 'audience', where they observed and were emotionally moved or a 'soloist' waiting to perform. Three subordinate themes represented these elements: 'Everyone plays their part', "there are things that you can't really control" and "someone they know". Maintaining control was facilitated by an informed and experienced team, where *'everyone plays their part'*, ensuring safety would be preserved, unexpected events minimised and patient comfort optimised:

"...made sure that we've all discussed what's happening beforehand so there's no surprises, there's nothing suddenly happens that you weren't expecting" Chris (Page 6, Lines 6-8)

"...if you have the right team, and you are meticulous, and you take care with your set-up and your operation, and how you assess, have a methodical way of assessing language, and all those elements of it, then it can be a, you know, it shouldn't be a major deal to do an awake craniotomy" Mark (Page 10, Lines 21-26)

Team members emphasised the importance of having an informed and experienced team who managed additional inter-relating elements in an effort to minimise "stress levels" and maintain control. These included: ensuring equipment was prepared, organised and operational for surgery, guaranteeing patient comfort by addressing position and adequacy of regional analgesia, limiting patients' exposure to adverse visual stimuli, and avoiding distraction from the presence of unnecessary "theatre traffic":

"It's making sure that all the little tools, instruments, that you have are going to be catered for before, because what you want as well is you want nothing to do on in that theatre that's going to raise your own stress levels. Uhm, you know, if someone says to you, 'Oh, I haven't got a suture to allow you to do this', you'll say, 'Well, hang on. I always use a suture. Why don't you have it?'" Daniel (Page 10, Lines 39-46)

"...you've got to get the patient position right, looking comfortable, in pins properly, you've got to make sure you've got enough anaesthetic in, local anaesthetic and they're going to be comfortable when they wake up" Mark (Page 4, Lines 37-40)

"...we try not to let them see the intraoperative imaging that we're using, our guidance systems, in case that would put them off" Brian (Page 7, Lines 11-13)

"I think if there's too much going on, there's too many people, that's not helpful" Julie (Page 10, Lines 10-12)

Derick was especially eager to describe the importance of enforcing "*rigorous theatre discipline*", sentiments endorsed by Chris, Mark, Daniel and Julie. It appeared imperative to "*eliminate*" all "*unnecessary conversations*", "*light-hearted banter*" and "*loud noises*" since these distracted the neurosurgeon and concerned patients as to "*what the hell (was) going on*":

"It's absolutely imperative that people behave themselves in the operating room. That means superfluous and unnecessary conversations are basically eliminated. It's bad enough when you've got somebody whose sleeping. The surgeon is trying to concentrate and people are talking in the background is utterly unacceptable when you've got somebody awake" Derick (Page 5, Lines 35-41)

"...there's no sort of light-hearted banter particularly on these, for these cases" Mark (Page 4, Lines 46-47)

Given the presence of an awake patient, importance was also placed on the neurosurgical team changing or adapting their communication style. This was believed to avoid *"drawing the patient's attention"* inadvertently towards their surgery, thereby minimising distress and conserving the neurosurgeon's control. Derick and Daniel emphasised how altering communication was crucial when a surgical problem arose and Gill believed an informed and experienced team optimised this practice. Joyce also considered usage of non-verbal communication was helpful during AC:

"But when you've got somebody awake, you've now got a bleeding point inside the head which you're going to have to deal with, but with minimal fuss, so that's not to disturb the patient which changes one's communication style" Derick (Page 5, Lines 22-25)

"If the patient gets any idea that something is not quite right or it's not going to plan, then that raises anxiety levels. And as I said before, raised anxiety levels, hypertensive, pulse goes up. That can change what's going on at the operative side" Daniel (Page 10, Lines 27-30) "So, we don't always want to kind of say, 'I want to know whether the surgeon is actually resecting at the moment, and I need to be testing'. You don't necessarily want to ask them that, because that's drawing the patient's attention back to the fact of what's going on behind them. Uhm. So actually, just being able to see that...so, some of that non-verbal communication is really helpful" Joyce (Page 8, Lines 38-45)

Team Subordinate Theme 2.2: "There are things that you can't really control"

Despite attempts to preserve control within the operating theatre, team members acknowledged *"there are things that you can't really control"*. The awake patients' level of alertness, emotional state and associated ability to co-operate with intraoperative tasks was considered unpredictable, even after preoperative preparation, introducing 'uncontrollability' and stress to proceedings. It was felt high levels of patient anxiety compromised safety and the ability to collaborate with the neurosurgical team, requiring appropriate management:

"It's not made easier if the patient is very anxious, and we have had patients who would hardly talk to us. And we really want patients just to talk as much as possible, strangely enough, because it's fantastic feedback" Brian (Page 5, Lines 19-23)

"Less predictable is how the patient will actually react to you and even if you've done a really good assessment and feel the person, you know, has got some coping strategies" Julie (Page 7, Lines 44-45 to Page 8 Lines 1-2) Team members described how it was difficult to 'focus' and remain objective on operative tasks in the presence of an awake patient. Mark highlighted how *"bizarre"* and *"crazy"* it was to operate on a patient's brain while they are awake, laughing in disbelief at the concept. Brian described how having a patient awake restrained his ability to be objective when operating, heightening the *"sense of harm"* he might do. Lack of objectivity contributed to the stressful nature of AC, requiring team members to manage their emotional reactions to retain control:

"I mean, it's just bizarre, isn't it? I mean, it's crazy (*laughs). You've got someone's head open and they're awake. And they're, you know, you're stimulating and you're causing speech arrest" Mark (Page 5, Lines 17-20)

"There is talk among surgeons that it's much more easy to operate on someone if you're objective rather than thinking this is who it is. So, if you're just operating on an operating field on a brain, rather than operating on Mrs Smith. With someone's who's awake, you can't have that objectivity, because you know exactly who you're talking to. And you're often talking to them quite chattily about mundane matters. So, you certainly know you're dealing with a particular patient which heightens, I think, the sense of harm that you might do" Brian (Page 4, Lines 39-47)

Chris and Daniel also explained how their ability to remain *"focused"* was constrained by requirements to reassure and communicate with patients. Daniel further stated how he could *"switch off"* when a patient was *"chattering on"*, adversely affecting his ability to monitor functional assessments: "...sometimes you have to reassure the patient and chat to them and things like that rather than just getting on with what I'm doing" Chris (Page 5, Lines 23-25)

"...if someone (patient) is chattering on the whole time, you yourself will kind of switch off from all that which is not a good thing" Daniel (Page 12, Lines 36-38)

The presence of an 'awake' patient required "focused" coordination of unique interrelating operative "elements", absent when utilising general anaesthesia. 'Conducting' team members and procedural "elements" required "focused" usage of cognitive resources to maintain control in the face of the continual challenge of being unable to predict a patient's response or their ability to cooperate. Chris, Mark and Brian explained how these competing and sometimes uncontrollable demands caused stress for them as neurosurgeons, making them become more "focused" and controlling to cope:

"It is slightly more stressful because not only am I doing you know, although the operation I find fine, you know, I've also got to deal with the patient there and I'm, rather than just focusing in on taking the tumour out, I've got to think about more things. I've got to think about functional aspects. I've got to think about where I'm stimulating. I've got to think about integrating what I'm doing with what the speech therapist is telling me and what the patient is telling me. And so there is more going on at any one time and as a surgeon it's easier for me to focus in on one thing than a bunch" Chris (Page 5, Lines 12-21) "...it is a stressful operation for the surgeon. Because of all the extras that we don't normally have to cope with, with patients who are asleep" Brian (Page 4, Lines 36-39)

Other members of the team were felt to be in a parallel process with the neurosurgeon, describing an *"intense concentration and focus"*, particularly when conducting intraoperative assessment of a patient's functioning. This *"hyper-aware"* state was interpreted as an extension of the neurosurgeon's *"focus"*, allowing the *"conductor"* to preserve as much control as possible, given a patient's unpredictability:

"I'd say, hyper-aware; is that a subtle change in speech? What's happening there? Is the patient actually just a little bit sleepy?" Joyce (Page 7, Lines 44-46)

"It's a bit like a vigilance task that you absolutely have to spot when something happens but the vast majority of the time, nothing's happening. So it's, it's, it requires sort of intense concentration and focus throughout" Julie (Page 7, Lines 10-13)

It was felt that team members' recognition of AC as being stressful and requiring *"focused"* cognitive resources resulted in preparatory coping strategies to facilitate control. Mark explained how he only allocated a single AC case for the entire day to avoid any distracting thoughts about other operations. Daniel stated how he prepared himself psychologically before the procedure to enhance a *"focused"* demeanour. Julie ensured that she appeared calm and comfortable during the operation by undertaking an

established routine of eating, drinking and dressing appropriately beforehand, which she believed assisted patients to feel relaxed:

"I only generally put a single case on, especially with language mapping, single case on for a whole day. Because what's the point in thinking you've got another case to do after this" Mark (Page 3, Lines 46-49)

"I just tend to kind of make sure I have a few quite moments" Daniel (Page 9, Lines 26-27)

"I have my little routine before I go down which involves eating and drinking (*laughs). And, you know, and dressing appropriately so you're not too hot and not too cold, you know. Just so you can sustain, because obviously you want to be the best for the patient, because they need to be able to get from you, you know, this is going okay. We're calm. It's fine" Julie (Page 7, Lines 18-23)

The high level of intraoperative anxiety experienced by team members was evident from the sense of *"relief"* and *"elation"* manifest at the end of the *'final movement'*:

"...there's a big sense of relief where they say, 'Right! That's it. We're going to close up now'. A big sense of relief at that point" Joyce (Page 7, Lines 47-49)

"I think probably towards the end of the procedure, once that, you know, everything's gone to plan and, uh, you know, we're closing up the wound, I don't mind saying that I probably feel a slight sense of elation that it has gone fine" Daniel (Page 9, Lines 30-34)

Team Subordinate Theme 2.3: "Someone they know"

Team members considered 'awake' patients to experience a diversity of emotional reactions within theatre which influenced professionals' preservation of control. Disparate views emerged surrounding how patients felt during AC and this was perceived to reflect team members' varying insight and inquiry into their clients' intraoperative experiences. Team members often expressed hesitation, as indicated by Mark's laughter, when attempting to describe their knowledge of a patient's intraoperative perceptions, which was thought to reflect a lack of understanding:

"I guess this interview has revealed that I don't have much understanding of patient experience! (*laughs). Erm. Because, because maybe I don't ask" Mark (Page 11, Lines 4-6)

While some team members considered patients to be *"anxious"*, upset, shocked and surprised, others perceived them to be relaxed:

"...it's not uncommon for people to become quite emotional during the procedure and obviously very common for people to be anxious" Julie (Page 9, Lines 13-15)

"They are surprised to find themselves in that environment. And I think they probably stay in a state of shock throughout the process" Brian (Page 6, Lines 20-22)

"...the majority of patients we've had with one exception have actually been very relaxed throughout the whole thing" Derick (Page 6, Lines 9-11)

Team members also described diverse views surrounding a patient's ability to remember their intraoperative experiences. Chris, Mark, Joyce, Daniel and Julie explained how patients exhibited varying degrees of recall, some remembering *"everything"* or *"most of it"* while others had limited retention. In contrast, Gill was adamant that patients had *"absolutely no recollection"* of the procedure and Derick attributed this to amnesic effects of administered anaesthetic drugs:

"Some have very clear ideas that they can remember everything and some of them don't recall very much at all" Mark (Page 6, Lines 18-19)

"The patients have no recall whatsoever of the procedure, that's what we've found. That's partly due to the general anaesthetic, given before the start of the procedure, this causes amnesia for about an hour after you finished giving them the drugs" Derick (Page 7, Lines 21-25)

Although understanding of patients' experiences appeared diverse, it was acknowledged that a patient's emotional reactions were varied and unpredictable during theatre, requiring tailored control to ensure safety. Consequently, team members described how they utilised previously established patient-practitioner relationships in an attempt to contain their patients emotionally. This "therapeutic relationship" was employed to incorporate patients into the neurosurgical team. Patients were felt to become like part of an "orchestra", where expectations were placed on them to perform properly, rather than being "lonely" and "emotional" in the 'audience'. However, the fact that team members described an "intense focus" on multiple operative "elements" may indicate their patients felt isolated at times, being treated more as a 'soloist' who collaborated with an "orchestra", but only when 'conducted'.

Chris, Joyce, Derick and Julie explained the importance of having a team member who had established a preoperative *"relationship"* with the patient, being dedicated solely to providing emotional containment and reassurance throughout AC. Chris believed the presence of a familiar practitioner facilitated the patient's communication of any concerns while Julie stated how knowledge of a patient's personal details and coping strategies assisted her to provide reassurance:

"I think what they find helpful is to have someone they know, to be able to talk to, to know that I'm able to listen to what they're saying as well as the anaesthetist and to deal with any problems" Chris (Page 7, Lines 17-20)

"I think what they find helpful is (*pause), having a good relationship with a member of the team, who is usually the psychologist because that's the person that they spend most of the time with and who was there throughout" Joyce (Page 10, Lines 46-49)

Mark believed having a familiar person sitting close to a patient throughout AC facilitated patient cooperation with intraoperative assessments, thereby maintaining control. Joyce further described having a *"working relationship"* with patients, where it

was felt both parties shared an experience of proceeding through surgery and intraoperative tasks together:

"...when they wake up, there's someone that they recognise And so that they aren't having to think, 'who is this person sat in front of me?' They know it's, you know, my speech therapist or the anaesthetist. And presumably, that means that they'll interact better and give us a better response" Mark (Page 5, Lines 43-48)

"...a good kind of working relationship with a key member of the team who's going to communicate the most with them throughout" Joyce (Page 11, Lines 15-17)

Team members described their use of various strategies to provide patients with reassurance and manage aversive emotional reactions, although they seemed unsure how best to facilitate this. Daniel, Gill and Julie considered the use of physical touch provided their patients with reassurance. Gill elaborated on how 'hand-holding' felt an *"instinctive nurturing"* response, where attachment was compelled towards a patient, given their situation, conveying a message that no harm was intended. This may explain why Julie believed touch to be appropriate within a theatre environment but not in other patient-therapist contexts:

"...patients have come back and sort of said, you know, 'Who's that who held my hand the whole time through, you know, that was really reassuring and...' I think they always remember that, you know, it's always a kind of, you're doing something that maybe feels instinctively nurturing because they're in a position of vulnerability, just to demonstrate that, you know, you mean no harm" Gill (Page 12, Lines 26-32)

"I often uhm, hold hands with the person which is again maybe not, definitely not something I do in any other patient-therapist situation, but it feels very appropriate" Julie (Page 10, Lines 12-14)

Joyce explained how she attempted to distract a patient's attention from their surgery by engaging in conversation or rehearsing intraoperative assessments. Julie also employed distraction through the use of deep breathing exercises in an attempt to keep patients calm:

"...you take their full concentration and keep them busy. I think that's the most helpful thing for them" Joyce (Page 11, Lines 36-37)

"...we might need to do deep breathing with somebody during the procedure just to try and keep them calm and distract them" Julie (Page 9, Lines 15-17)

Finally, Joyce reported how appropriate use of humour can help *"lighten the mood"* when patients are faced directly with the enormity of brain surgery:

"I think they appreciate and find helpful anything that does actually kind of lighten the mood. So actually, the use of humour in theatre can be quite good" Joyce (Page 11, Lines 24-26)

Postoperative

Patient Group

Patient Superordinate Theme 4: "You start to realise what you've been through"

This superordinate theme captured how, during their recovery, patients began to realise and acknowledge what they had just been through and what was to come:

"Suddenly you've got this big bloody bandage on your head and you start to realise what you've been through" John (Page 15, Lines 23-24)

Patients' initial feelings of shock and powerlessness surrounding diagnosis and impending surgery limited their ability to fully contemplate such rapid events before AC. Patients' desire to "get rid of it" combined with the neurosurgical team's advice to undergo AC as soon as possible, may have "lulled (them) into a false sense of security" where a cure could be anticipated, allowing them to obtain control over a previously powerless situation. After the procedure, patients suddenly seemed to be faced with the stark reality of their circumstances, contradicting previous expectations, thereby evoking significant emotional reactions. Several patients reported how being told most of the tumour had been resected led to unrealistic expectations surrounding their prognosis. Moreover, despite preoperative notification about the possibility of experiencing deficits after surgery, patients were often shocked if they occurred, although preparation assisted some patients to manage difficult feelings:

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"...the thing that did annoy me was the fact that I had, I just thought I was going to come back normal" Joan (Page 12, Lines 9-10)

"And I couldn't move, couldn't move anything. It was horrible. And I felt...really, uhm...How did I feel? I was frightened. Yes. And I thought, 'Oh! This is it'. Because I'd been for some reason, I'd been convinced that it wouldn't happen to me. Uhm...I don't know why because (*pause), I've read all the, you know, the likelihood, the possibility of it happening so...And normally, I am a very pessimistic person. So I'm surprised that I didn't think it might happen to me." Tess (Page 6, Lines 45-50 to Page 7, Lines 1-3)

Overall, patients' sudden realisation of what they had just experienced, awareness of postoperative deficits and an insight that AC had not been curative, resulted in them experiencing a journey of adjustment. Two subordinate themes illustrated these elements: *"you've got to fight through this"* and *"learning to manage"*.

Patient Subordinate Theme 4.1: "You've got to fight through this"

Patients' sudden realisation of their circumstances provoked an *"emotional and physical"* adjustment process that they had to *"fight through"* during the initial stages of recovery:

"I didn't expect to come round and my arm be paralysed so, um, that is my kind of first memory, um, and the kind of, the battle, an emotional and physical battle that I went through with the kind of, trying to deal with that" John (Page 20, Lines 48-50 to Page 21, Line 1)

"You've got to fight through this" Joan (Page 7, Line 18)

At first, patients seemed unable to cope with the stark reality they faced, articulating various psychological reactions including shock, despair, hopelessness, low mood, uncertainty, anger, frustration and anxiety:

"...you start thinking 'oh my god, that's it, I'm not going to be here in a few, in a few years' time' and I think that's when I started thinking, 'bloody hell, this isn't something that's going to go away'" Mary (Page 10, Lines 12-15)

"I thought I'd never get better quite honestly at first" Tess (Page 7, Lines 4-5)

"I'm not going to use the word because I'm on tape but, you know, everything is about as low as it could possibly be" John (Page 17, Lines 22-24)

"I got this anger, all came about me, and I got cross because uhm, say I'd put an order in for my meal, my dinner, I couldn't remember what I was having" Joan (Page 6, Lines 29-31)

"I'd wake up sweating but that wasn't, it was caused through this anxiety or whatever it was and I did start fighting that" Joan (Page 7, Lines 23-25) Patients appeared to ruminate on their circumstances in response to these psychological reactions which seemed to provoke and maintain difficult feelings. They reported pondering the likelihood of a successful recovery, whether AC had been the best option and if acting earlier on subtle signs could have improved current circumstances:

"You've just got a lot of thoughts going through your head... 'Is this going to be okay, is that going to be okay?" Ryan (Page 11, Lines 11-13)

"He (Neurosurgeon) did say in his letter that if I'd have had an anaesthetic, you know, it would have been worse, I don't know how they work that one out, but he said it would have been worse" Elaine (Page 6, Lines 48-50 to Page 7, Line 1)

"I said there was, there was nothing wrong with me but there obviously was but just tiny things that nobody would really have noticed and finding words, that was something I really did notice" Mary (Page 10, Lines 40-43)

In response to their adverse psychological reactions, patients wished to utilise their previous strategy of attaching to the neurosurgical team in order to feel emotionally contained. However, this appeared constrained by lack of team member availability and focus on early discharge, consequent upon a prescriptive routine of clinical care, with potential to exacerbate adverse psychological reactions:

"...the night staff, they just come...the beds are checked. I got told they should check on you and stuff like that. They just come and just stick the

monitor on your arm and they'd be there all night, and they didn't come back" Ryan (Page 7, Lines 41-44)

"I think it was the following morning he said, 'oh, you'll be out of here tomorrow, Andrew'. And I said, 'oh'. I was kind of like...so I think I said, 'I've not even been to the toilet yet, Mike'. He said, 'I know'. I think it was a problem with beds and then...I went out the following day trying to kind of stand up and walk around" Andrew (Page 9, Lines 5-10)

In self-contradiction, Tess and John also described feeling supported by their care staff. It was possible that patients felt obliged to avoid criticism of their team, being indebted having just survived the procedure. Alternatively, patients could have been referring to certain members of their team with whom they had managed to develop significant relationships:

"I just felt very supported. The (*pause), all the nursing staff, everyone in (town) was just...couldn't do any...they couldn't have done more to help" Tess (Page 10, Lines 10-12)

However, some patients reported feeling completely supported postoperatively, highlighting the importance of sensitivity to idiosyncratic needs and provision of timely information surrounding their recovery and possible future treatment: "...well the staff were fabulous on the uhm, ward, uhm, yeah you felt as though, as though if you ever wanted anything there was going to be somebody there to help you" Mary (Page 8, Lines 21-24)

"...the specialist nurses, they were very good at keeping me informed and...and...it does make me feel that I've been looked after" Tess (Page 10, Lines 16-18)

Patient Subordinate Theme 4.2: "Learning to manage"

Patients described a process of *"learning to manage"* and adjust to their circumstances thereby slowly alleviating initial aversive psychological reactions. Recovery was felt to take some time, comprising rehabilitation of deficits, integration once home and undergoing future interventions. It appeared patients were motivated by a strong desire to regain a sense of 'normality' and 'control' over their lives:

"...it's taken me a while to, it took me a while to, learn to manage, but I do it now" Joan (Page 7, Lines 40-41)

"...you just had brain surgery and you just know that you have to recover. Um, and you know that'll take a little bit of time" Andrew (Page 12, Lines 16-17)

Patients began to develop a sense of hope, contrasting previous negative feelings. Hope appeared pivotal in empowering patients' beliefs that some resolution of their current

circumstances was possible, enabling positive adjustment throughout difficult circumstances:

"...with a bit of luck, normal old age will get me before that does" Joan (Page 9, Lines 39-40)

"...here I am, two and a half years later nearly (*laughs), so, and uhm, they were right, the tumour came back in my July scan so uhm, I'm not dead yet (*laughs), but it has come back so, but uhm, the chemotherapy is working at the moment" Jane (Page 13, Lines 12-16)

John emphasised how his relationship with the team was essential for developing and maintaining hope:

"...we did a very short, well, probably half an hour physio session, but enough that, you know, it showed little bits of positivity and reminded me that actually, you now, the arm was moving forward even though very slowly" John (Page 17, Lines 47-50)

While hope motivated and maintained patients' adjustment to their circumstances, *"learning to manage"* also involved recognition that their world had changed:

"I'm not in a world that I was in before" John (Page 21, Lines 30-31)

This 'new world' appeared characterised by persistent uncertainty over whether the tumour would return. Joan, Elaine, Andrew and Ryan all expressed how their lives now

consisted of serial MRI scans to monitor the tumour, being unsure of whether "*it*" would return or if future treatment would be required. Patients' attempts to maintain independence and retain control remained compromised by the powerful influence exerted by their BT.

"I mean I have the MRI scans every year, uhm, and if, I mean (*laughs), cross my fingers, if they said the tumour was growing back or anything, we'd have to do the operation again" Elaine (Page 8, Lines 36-39)

"Am I going to have to go through all that again? Am I going to have it all opened up? Which he (Neurosurgeon) did say...they might have to open it up and just have a look. So it's still not finished, it never will be finished. So you live your life six months at a time, from scan to scan" Ryan (Page 11, Lines 33-37)

In this 'new world', prognostic uncertainty also appeared to impact the patient's family. Jane explained how her adjustment involved planning ahead with her husband in case she became incapable of making decisions which was particularly distressing:

"I told him (husband) that if I went really down-hill and, sort of, couldn't communicate anymore and everything that I didn't mind if he found another partner" Jane (Page 14, Lines 1-3)

Jane and Tess described how this altered world now included further treatments which acted as a constant reminder of the BT's influence over their lives:

"...he'd (neurosurgeon) told me, you know, sort of, what the recommended follow up treatment would be, and that was combined radiotherapy with chemotherapy for six weeks, every day for six weeks and then a four week gap and then six months of chemotherapy" Jane (Page 12, Line 18-22)

"...any rogue cells, I wanted them zapped and yeah, I was happy to have that one. I think I was scared of having chemo, which I haven't had yet. I mean I could if I needed it later on" Tess (Page 11, Lines 6-9)

The majority of patients acknowledged that "*learning to manage*" involved becoming a changed person, where identity was altered from before BT diagnosis and AC. Jane, Elaine, Tess and Ryan reported how they had lost a part of themselves attributed to their diagnosis, the physical removal of part of their brain, presence of postoperative deficits and continuing treatment. This resulted in an inability to engage in previous activities, thereby limiting patients' independence and making "*life difficult now*":

"There are things I can't do now, like ride my bike and put on my high heel shoes and walk very far, I used to do a lot of walking in the Lake District with the family and uhm, a lot of cycling and things like that but I can't do that now" Elaine (Page 6, Lines 44-48)

"...the driving, that's the main thing – the driving. Cause I'm told I couldn't drive a year after. I think if I could...if I could drive, it would take my mind off it. But because I can't drive, it's so annoying. That would be the hardest part of recovery, getting that licence back" Ryan (Page 8, Lines 43-48) In contrast, patients also reported how being a changed person resulted in gaining beneficial aspects to their character. It appeared challenging circumstances highlighted what was truly important:

"I think well I'm alive and I wouldn't have been if anything, if it had been left. So...I'm very lucky and I feel very well" Tess (Page 11, Lines 32-34)

"...it's taken something away from me, but to have movement is such a blessing" Jane (Page 13, Lines 27-29)

"I suppose I was lucky that it didn't affect me, my brain, well it did affect my brain because that's (*points to foot) brain damage from my foot, but it didn't affect my thinking" Elaine (Page 8, Lines 1-3)

Patients reported how ongoing support from their team was crucial for *"learning to manage"* with these changes in an uncertain world. Knowing the team were available provided patients with emotional containment, comfort and safety, especially if something were to change in their health status, avoiding feelings of isolation after discharge home:

"I mean genuinely compassionate caring people that I genuinely believe made a difference to my recovery, uhm, and I do genuinely believe that and I genuinely think they have also helped me move forward, you know, post everything" John (Page 21, Lines, 24-28) "I've nothing but praise for them because they, they are the contact point and they do know their stuff and they are reassuring when they get in touch" Jane (Page 14, Lines 36-38)

"I feel, uhm, like they've placed me in some sort of a comfort blanket that I know I'm within, that if I would uhm start banging on the edge of this blanket then they would, they would come see me. So I feel quite confident with that" Andrew (Page 11, Lines 3-7)

Ryan explained how absence of ongoing care made adjustment following surgery very difficult for him. The sole focus on medical aspects of his care limited his ability to communicate feelings, invoking anger, frustration and a belief that his neurosurgeon *"didn't care"*. It was felt that his reaction also highlighted a crucial need for comprehensive assistance following discharge:

"He said, 'well, we're going to scan you in six months.' And that's all they want. They weren't interested in anything else. Because obviously these are neurosurgeons so that's the only person you see. So he won't...He didn't care about what else was doing on. He just cared about the tumour and what (*pause), what action to take and that was it." Ryan (Page 13, Lines 1-6)

In contrast, Joan did not wish to receive support after discharge, preferring to remain as independent as possible, because any assistance acted as a reminder of her condition:

"...they've kept ringing up and saying do I need them but I haven't thought that I needed them and the less that I have to do with this, to me, is better" Joan (Page 9, Lines 10-13)

Neurosurgical Team Member Group

Team Superordinate Theme 3: 'Recovery'

This superordinate theme captured how team members described their patients' postoperative recovery highlighting several "*aspects*". Interestingly, accounts of the care provided following AC were significantly shorter than other treatment phases, perhaps reflecting less involvement from team members. It appeared a predominant focus was on the rapidity of a patient's physical improvement, evidenced by team members' usage of medical language and terminology; accordingly patients were believed to require minimal support. In contrast, while there appeared diversity in team member insight, patients were recognised to undergo a huge "*change to their lives*" as they adjusted to the realisation of BT diagnosis, undergoing awake brain surgery and procedural outcome. Throughout this adjustment period, appropriate ongoing support was acknowledged as imperative for a patient's recovery. Two contrasting subordinate themes represented these elements; "*straightforward physical recoveries*" verses "*they often come down with a big bang*".

Team Subordinate Theme 3.1: "Straightforward physical recoveries"

Team members focused consistently on the physical "*aspects*" of a patient's recovery, being informed by a "*medical model*". The majority of patients were believed 180
to have "*straightforward physical recoveries*" where they would quickly feel "*back to normal*". Accordingly, postoperative care comprised *routine*" practice where patients who had undergone AC were considered "*identical*" to "*other oncology patients*" and therefore managed similarly:

"...they've all had very straightforward physical recoveries sort of very quickly and certainly back up on their feet feeling physically back to normal" Julie (Page 11, Lines 35-37)

"...they are the same person that came in to the anaesthetic that goes out. It's just they happen to have a craniotomy and a wound on their head" Daniel (Page 13, Lines 33-35)

"So postoperatively from a management side, it's identical to anybody else uhm, so it's fast, as far as management is concerned, we don't really do anything differently" Derick (Page 8, Lines 5-7)

"Routine post-op care" was felt to incorporate several *"aspects"*. This comprised infrequent visits where the results of surgery, possible need for future treatment and the implications of any postoperative deficits were discussed. This information conveyed to patients the level of control which continued to be exerted by their BT:

"Postoperatively, they, uhm, you know, they (neurosurgical team) will all make one visit each, I mean they might even see them a couple of times but, uhm, and then on the whole that will be it, there won't be any other reason for them" Daniel (Page 15, Lines 13-16) "...the patient meets again with the operating surgeon, whoever that was, to get their results and to get any advice regarding further treatment if required" Joyce (Page 14, Lines 17-19)

In accordance with a *"medical model"*, all team members viewed *"a good outcome"* to incorporate maximum safe removal of the BT with a physical recovery focus emphasising minimal or no neurological deficit:

"...if someone's got a low-grade glioma and I'm able to take out more than 95% of the tumour, they have no increase in their uhm, neurological deficit and they get out of hospital quickly and have no complications" Chris (Page 8, Lines 48-50 to Page 9, Line 1)

"...a good outcome for me will be a patient who's had all the tumour removed. And is as, well, as perfect as they were beforehand or, you know, certainly no worse than they were" Daniel (Page 15, Lines 31-34)

Mark, Joyce, Julie, Gill and Brian believed their patients recovered quickly, requiring only a brief stay on the inpatient ward. It was felt that team member's focus on *"routine"* discharge planning encouraged or even pressurised patients to *"go home"*, despite Brian's acknowledgment that clients sometimes felt anxious or hesitant about leaving hospital so soon:

"...their staying on the in-patient ward actually, is really quite brief" Joyce (Page 14, Lines 21-22)

"...we usually say to them, 'You should be fine to go home the next day.' They often feel a little bit unsure about that. They tend to go home the following day. So, the second postoperative day. But we would be encouraging them to go home the next day. They don't like doing that" Brian (Page 7, Lines 38-43)

Following discharge, team members described the paucity of their involvement with a patient's ongoing care, consistent with a belief that they had recovered. However, Gill acknowledged that patients can often feel *"isolated"* when discharged home and supplied contact details for various support services, although responsibility to seek ongoing care appeared to be delegated to patients:

"...as far as my post-case management clinic follow up is concerned, I just reassure the patients again that they, they don't have any problems" Derick (Page 8, Lines 7-10)

"...they've got, uhm, like an information booklet pack. So it's like, you know, it's got all kind of bits for putting extra leaflets in and lots of contact details for all the support groups. So when they go home, there's not so much that feeling of isolation" Gill (Page 16, Lines 37-40)

Team Subordinate Theme 3.2: "They often come down with a big bang"

During a patient's recovery, team members described how it was important to remain aware of *"the context that they've got a brain tumour"* which was felt to be *"the*

hardest thing" to process. Although patients had been warned preoperatively about the possibility of experiencing postoperative deficits or how their BT *"could turn cancerous*", they were felt to have *"their hopes enormously high*". While hope may have empowered patients to undergo AC, it remained possible that it also compromised their ability to acknowledge potential adverse outcomes. Mark, Joyce and Brian explained how patients frequently have optimistic expectations regarding AC being a curative process, *"often com(ing) down with a big bang*" and being *"more down for having had this*", when suddenly realising the reality of their circumstances:

"...so often, the patients might come into it expecting that if you take it all out, they might think it's benign. They might think you're curing them" Mark (Page 9, Lines 10-13)

"...they often have their hopes enormously high. And I think they often come down with a big bang when they realise that they're still not getting a hundred percent reassurance from us. And I think they'd often hoped we will say, 'That's it. You've had an operation. It's cured. Forget it.' And then suddenly realise it's not like that" Brian (Page 8, Lines 39-44)

During the early postoperative period, team members acknowledged a variety of reactions from their patients. Some appeared *"shell-shocked"* at the *"enormity"* of their diagnosis, experiences of AC and appearance of postoperative deficits while, in contrast, pride and relief was evident in others:

"...in that early postoperative period, they're often a kind of a little bit shell-shocked, stunned, that actually, the enormity of it, is that when they're *in recovery, they realise they just had a brain operation awake" Daniel* (*Page 13, Lines 43-46*)

"...some are very proud of the fact that they've been, that they successful got through it" Chris (Page 9, Lines 22-23)

"...they're relieved to know that they've had something done and this is maximum safety as opposed to potentially taking a risk and causing them problems" Derick (Page 8, Lines 14-17)

Following discharge, team members acknowledged patients responded in a variety of ways. Accordingly, some patients were disappointed upon realising AC had not been curative, questioning the wisdom of accepting surgery while others appeared to *"get on with"* the reality of their predicament. Patient individuality was felt to influence adjustment towards BT diagnosis, treatment and surgical outcome:

"...when you tell them afterwards that it's, let's say, you know, a low-grade glioma. It's going to grow back. But, we need to keep an eye on it, and all the rest of it, I think people...patients have probably, some of them can be disappointed in the outcome. Uhm. They're thinking, 'Well, why did I go through all that if it's going to grow back anyway? Other patients have, you know, just get on with it. Take it and just say, 'Okay. I know what I'm dealing with'" Mark (Page 9, Lines 19-27)

"This is quite difficult trying to split out the elective low-grades and the high-grades because they're very, very different groups of patients. Completely different prognosis. Completely different decision-making processes that we're talking about earlier. It makes, obviously, a key thing that makes a difference is whether or not, in the weeks and months after surgery, whether or not they need to have further treatment" Joyce (Page 13, Lines 23-30)

Team members described how a patient's sudden realisation of what they had just experienced, an awareness of postoperative deficits and insight that AC had not been curative resulted in a huge *"change to their lives"*. *"Learning to manage"* was considered a lengthy physical and psychosocial adjustment process for patients, having to cope with longer term effects of fatigue, adaptation to postoperative deficits, the impact of further treatment, and persistent uncertainty surrounding prognosis:

"...physically, you're likely to be better very quickly, but don't underestimate the amount of time before you're fully back. And so fatigue ...like that I really emphasise that as well because I think that's a big one and that's one of the persisting factors and it obviously makes the cognition uhm, difficult to do much more prominent, and people can get quite frustrated and potentially a bit down thinking 'Oh'" Julie (Page 12, Lines 2-8)

"...there's quite a lot of anxiety and self-doubt, uhm, about, uh, not only about their cancer diagnosis but also about their ability to communicate with other people" Gill (Page 14, Lines 39-41) "...then have to go through radiotherapy and chemotherapy, and that floors them, and they say they can't believe that, you know, surgery was nothing and walked through that and coped really well, and that's fine, but actually, this has floored me. And its lots of reasons, like, you know, whether they're thinking radiotherapy, chemotherapy was very unpleasant, it was intensive, you've got to do it daily. It's not just one thing that you get over in a day" Julie (Page 13, Lines 18-24)

"...they're going to continue having that yearly surveillance scan at least. We're never going to tell them for sure it's gone. And I think a lot of patients find that very difficult. And I've seen patients go from being very brave and upbeat to being very down" Brian (Page 8, Lines 45-49)

Throughout a patient's adjustment process, team members described how ongoing support was imperative to a patient's adjustment, providing *"head-space to process what they've actually been through"*. Ongoing care allowed discussion of concerns surrounding diagnosis, additional treatments and future uncertainties, enabling emotional containment, thereby enhancing patient recovery:

"...you've just been diagnosed with a tumour and you know, that can be quite a fast, uhm, process, with a bit of sort of psychological catch up time required, and that's another great thing about our role. We're like, they can have that time to, you know...process a sort of whirlwind" Julie (Page 14, Lines 7-10) Interestingly, Mark described how he was hesitant to approach adjustment issues with patients, believing this could evoke distress through unwanted focus on their diagnosis and compromise ability to "get on with life". It was felt that sometimes uncertainty existed surrounding how to address and discuss adjustment concerns with patients, possibly promoting avoidance of approaching the topic for fear of causing adverse reactions:

"...they don't want a constant reminder that this is a tumour that we can't cure and it's going to come back, ramming down their throats. That's what patients don't want. They want to get on with life. So, I tend not to bring up these issues" Mark (Page 10, Lines 1-5)

Although Brian acknowledged how patients required and *"want(ed) more support"*, absence of available outpatient clinic space compromised available appointments:

"...we see them in outpatients often at a protracted distance, because we don't have enough clinic space, and that's something we need to make better. So, I think we leave them too long afterwards, probably. I'm sure they would want more if they could" Brian (Page 8, Lines 17-21)

Nevertheless, a desire for optimal adjustment appeared to inform team members' views of "*a good outcome*", incorporating a patient's return to "*meaningful activities*" and "*life as they previously knew it*". Maximum resection without neurological or cognitive impairment optimised a patient's ability to psychologically and physiologically manage their circumstances:

"...the ideal outcome is that they can then return to their normal life and normal activities as they happened before" Gill (Page 18, Lines 5-6)

"...a good outcome for the patient is uhm, the maximum possible resection without disruption to cognitive function. And I say that as a psychologist uhm, knowing that there are obviously other factors. But I do think this is particularly special situation and that is a good outcome. So in terms of quality of life, mood, those sorts of things, they are best managed with that outcome. Because obviously, the...the more there is resected, essentially, the better the prognosis and the more intact their function is for them to return to valued and meaningful activities, and life as they previously knew it" Julie (Page 13, Lines 2-10)

Discussion

The study investigated the lived experience of AC and perioperative interactions for both patients and neurosurgical team members. Unique in utilising an IPA approach and in depth semi-structured interviews within a UK population, it explored patientneurosurgical team inter-relationships, focusing particularly on communication throughout preoperative, intraoperative and postoperative periods. The study findings endorsed previous qualitative research that underlined the individualistic nature of patients' AC experiences (Palese et al., 2008; Khu et al., 2010) and how practitioners perceived competing tasks of effectively communicating with awake patients while negotiating technical aspects of surgery (Palese & Infanti, 2006). Within each group, experiences of both AC and patient-neurosurgical team communication throughout the perioperative period were frequently inextricably related, could not be segregated, and are therefore discussed interchangeably. Results supported previous recommendations for usage of qualitative methodology when investigating complex personal and social phenomena within healthcare settings (Smith et al., 2009). The present investigation aimed to improve knowledge surrounding effective approaches to enhance such relationships by independently investigating both patient and practitioner perspectives simultaneously, as recommended by Salmon et al. (2011). Thereafter, unique results incorporating both groups have been synergised and compared with relevant literature for each stage of treatment. Contextual clinical implications and future research suggestions are reported throughout. Subsequently, study strengths, limitations and conclusions are presented.

Preoperative

Establishing relationships:

Through BT Diagnosis

Patients viewed the BT diagnosis as an integral part of their treatment experience whereas the neurosurgical team member group did not appear to consider the impact of BT diagnosis on appropriate relationship development during the first consultation. Findings endorsed previous qualitative research that described diverse patient and relative emotional responses resultant from BT diagnosis, with predominant feelings of shock, helplessness and powerlessness (Ownsworth, Chambers, Hawkes, Walker, & Shum, 2011).

Patients' appraisals of the BT diagnosis were influenced by interactions with practitioners. Current findings concur with Epstein and Street (2007) and Street et al.

(2009) that a professional's ability to communicate an accurate and timely BT diagnosis, while remaining aware of patients' informational and emotional needs, is crucial for positive relationship development, with potential to affect treatment experiences and adjustment. Janssen and MacLeod (2010) emphasised the importance of professionals being able to communicate effectively while being aware of patient idiosyncratic preferences. Specifically, Taillibert, Laigle-Donadey and Sanson (2004) highlighted the variation in how much individual patients wanted to know and discuss their BT diagnosis. The fact that patients considered BT diagnosis as an integral part of their AC experience is consistent with McWilliam et al. (2000) who reported effective communication and information provision during the first consultation was pivotal in developing trust with their practitioners, underpinning hope for patients with breast cancer. This is consistent with professional guidelines for communicating the diagnosis and disseminating information about BT that accentuate the diverse preferences that patients and relatives may have (Rosenblum et al., 2009). Emphasis is placed on the need to (1) calm fears, (2) discuss the science, (3) address the prognosis, (4) form a partnership with the patient and family, and (5) focus on the patient's and family's concerns. Current findings suggest patients' satisfaction is compromised when these guidelines are not achieved, consistent with Lidstone et al. (2003) who reported up to 25% of patents were dissatisfied with how neurosurgeons communicated their BT diagnosis.

Through sharing of information

Following their diagnosis, patients chose to place their complete trust in the expertise of the neurosurgical team while the latter attempted to comfort patients by displaying expertise and knowledge. Results suggested appropriate clinical

communication facilitated building and maintenance of patient-team relationships, underpinning trust and hope for resolution. In agreement with Salmon et al. (2011), it appeared that relationship building was best achieved when practitioners displayed their expertise according to patient preferences as a conscientious execution of their contracted role. Interestingly, this finding contrasts with communication literature which emphasises overt emotional exchange as prerequisite for building patientpractitioner relationships (Epstein & Street, 2007). Findings endorsed literature emphasising hope is anchored externally by attachment to others who could provide expert information during periods of helplessness (Bernardo, 2010), being pivotal in enabling patients to sustain diagnosis and subsequent treatment (Berendes et al., 2010). Invoking hope appears paramount in relationship development and it is recommended that the practitioners' role in building and supporting it warrants further research in BT populations.

Attachment theory offers a useful approach when interpreting study results. Attachments are emotional bonds that lead individuals to seek proximity towards a safe or powerful person when threatened (Griffin & Bartholomew, 1994). Adults seek evidence of the protective power of an attachment relationship and the other person's ability to ameliorate threat (Mikulincer & Shaver, 2003). Accordingly, when threatened by illness, it is practitioners whom patients regard as having the expert knowledge and information to provide safety (Wright, Holcombe, & Salmon, 2004). Therefore, patients were helped emotionally to feel secure and comforted through medically focused care from neurosurgical team members, which subsequently developed confidence to undergo surgery (Wright et al., 2004). This may explain why, in the preoperative phase, many patients desired practitioners to exercise authority associated with a medical model, consistent with Swenson, Zettler, & Lo (2006). Furthermore, in line with Helft (2005), companionship with expert practitioners offered safety in its own right and

created hope for resolution. If study patients chose to actively avoid information for fear of becoming overwhelmed by their impending surgery, relationship building may have become compromised, with patients delegating treatment decisions to team members to provide a sense of safety, adding to previous studies of Edvardsson and Ahlstrom (2005) and Fletcher et al. (2012). When faced with little contact from neurosurgical team members, Salander (2002) suggests patients may have constructed mental models of artificial ideological practitioners in an attempt meet idiosyncratic safety and dependency needs. Since practitioners' conscientious execution of their role appears pivotal to optimal relationship building and the development of hope, beliefs surrounding whether their contracted role includes a responsibility for adapting to patient preferences, based on emotional needs, requires further clarification.

The decision to undergo AC

Trust in the expertise of the neurosurgical team greatly influenced patients' decision to undergo AC, confirming previous reports of Khu et al. (2010) and Fletcher et al. (2012). While some neurosurgical team members emphasised the importance of a collaborative agreement with patients to pursue AC, others appeared to utilise their expert position to advocate choosing AC because it was 'safer'. Consistent with study findings, Lepola et al. (2001) reported variations in decision making processes, appearing dependent on whether patients wished to participate with or delegate to experts. The wide range of patient responses surrounding AC as a concept is a unique finding and may reflect exacerbation or containment of previous emotions evoked from BT diagnosis and sharing of information.

Study findings that some neurosurgical team members inform their patients that AC for BT is advantageous over general anaesthetic is concerning given a lack of

definitive objective data (Kirsch & Bernstein, 2012). Although, Peruzzi et al. (2011) have advocated the need for a randomised control trial (RCT) comparing awake versus asleep craniotomy groups, this raises significant ethical issues and is probably impractical. Accordingly, in the absence of comparative information, it is difficult for practitioners to provide unbiased recommendations to patients (Kirsch & Bernstein, 2012), raising concerns over the ability to obtain fully informed consent in this population (Bernstein & Bampoe, 2004). Practitioner awareness of personal preferences, possible bias and the power-imbalance between themselves and their patients therefore requires consideration when advising on the appropriateness of AC (Menges, 1973). Even then, some patients may still feel coerced into undergoing AC in order to avoid introducing negativity into a relationship which is perceived for ongoing safety (Bernstein, 2003). To complicate matters further, some patients feel overwhelmed by options presented and do not value choice, despite recommendations from health policy and clinical communication literature that it is imperative to involve patients in care decisions (Epstein, 2006). Consistent with Madjar, Kacen, Ariad, and Denham (2007), results confirmed that some practitioners felt an approach that prioritised patient autonomy could lead to damaging decisions perceived as incompatible with caring and beneficence. Given the complexity of obtaining fully informed consent, especially when AC is urgent, study findings highlight the interdependent dynamic between the level of power and expertise exerted by practitioners and the degree of patient vulnerability, including their preference for involvement in treatment decisions.

Although exclusion criteria for AC have been available for some time (Taylor & Bernstein, 1999; Blanshard, Chung, Manninen, Taylor, & Bernstein, 2001), several elements are subjective and these findings highlighted that disparate and often contradictory criteria were employed when selecting candidates. Consequently,

variation in the procedural selection is wide and may be influenced by a neurosurgeon's personal preferences. Surgeons' selection approach has also been ascribed to age (Irwin et al., 2005), experience and training background (Nassr et al., 2008), emphasising the need for development of comprehensive guidelines. In the interim, it is suggested that preoperative therapeutic enhancement of a patient's beneficial coping strategies may assist intraoperative management of emotions during AC (Albani et al., 2012).

Preparing for AC; managing anxiety

Members of the neurosurgical team considered it paramount to manage patients' anxiety while the latter described using diverse coping strategies for emotional containment when contemplating their impending surgery. Preoperative anxiety among patients is a common concern among health professionals (Pritchard, 2009) as it can lead to complications during and following surgery (Wong, Chan, & Chair, 2010). Present findings concur with a recent systematic review emphasising that education incorporating effective and consistent communication strategies, alongside provision of surgical information, was efficacious in reducing patients' pre-surgery anxiety (Alanazi, 2014). However, neurosurgical team members exhibited considerable diversity in the amount of material provided and whether a team or individual delivery approach was used. No standardised preoperative education curricula for patients undergoing AC exists and future development may be compromised since patients also exhibited variation in informational needs. Nevertheless, it is suggested that commonalities in content identified across team members may provide a preliminary framework for preparing patients and reducing anxiety by incorporating: (1) a rationale for pursuing AC, (2) a description of the operating environment, (3) an emphasis on the usage of local anaesthetic to alleviate pain, (4) the possibility of unpleasant operative events such as speech arrests and how to react to them, (5) encouragement to communicate any intraoperative concerns, (6) the rehearsal of any likely intraoperative speech or motor tasks, and (7) an emphasis on the real possibility of postoperative deficits. Delivery of such information may be optimised if practitioners are experienced with procedural elements (Paige, Aaron, Yang, Howell, & Chauvin, 2009).

Patients used this information provided by the neurosurgical team as a predominant coping strategy for emotional containment and preparation for AC. Findings endorsed Khu et al. (2010) and Manchella et al. (2010) who reported that patient confidence and preparedness for AC was enhanced through information provision and discussion of operative protocol. Rosenblum et al. (2009) advised that such information must be tailored according to patients' preferences for knowledge and their ability to assimilate, thereby ensuring timely delivery while avoiding feelings of being overwhelmed. It is also important to be aware that patients' defensive strategies could compromise assimilation of information, potentially compromising future cooperation, concurring with Milian, Tatagiba, and Feigl (2014). Future research and training is recommended surrounding how to communicate appropriate information effectively according to a patient's preferences while tentatively negotiating their defences.

Patients also used other idiosyncratic coping strategies, including avoidance, distraction, stoicism and humour to manage anxiety invoked from diagnosis and treatment appraisals, consistent with Palese et al. (2008) and Fletcher et al. (2012). By imparting specific expectations on patients to fully cooperate with requirements, the neurosurgical team may have inadvertently invoked usage of these coping strategies, which represented clients attempt to become helpful and assist the team. Coping has been defined as the cognitive and behavioural efforts used to manage demands appraised as stressful or exceeding resources (Lazarus, 1993). Findings emphasised a

patient's preoccupation with their anticipated intraoperative role consistent with Palese et al. (2008), possibly compromising an ability to process a BT diagnosis and information. Accordingly, early screening and support for psychological distress is recommended from the time of diagnosis (Janda et al, 2008), but how to optimise such a service in the context of impending and urgent surgery requires future investigation. Paucity of literature exists exploring coping strategies utilised prior to surgery for BT populations (Spijker, Trijsburg, & Duivenvoorden, 1997) or other serious conditions (Dropkin, 2001; List et al., 2002). The use of a virtual reality tool to replicate the surgical experience during awake procedures has been advocated by Albani et al. (2012), allowing patients to develop effective coping skills for reducing anxiety and improving collaboration. Future research is recommended to discover other efficacious coping strategies in BT populations. Given most strategies occurred within the context of the neurosurgical team, investigation is also warranted surrounding how practitioners can best facilitate coping to manage anxiety for prospective patients, with the potential to improve AC experiences.

Intraoperative

The psychological impact of AC

Patients in this study considered AC to be a bizarre and exclusive experience that was difficult to contemplate both during and following the event while members of the neurosurgical team displayed disparate opinions surrounding patients' psychological reactions. Some patients described periods when they experienced feelings of terror, distress, powerlessness and unexpected pain contrasting the majority of quantitative and mixed-methods literature surrounding patients' satisfaction (Danks et al., 1998; Goebel et al., 2010), acceptance (Wrede et al., 2011) and tolerance (Whittle et al., 2005; Wahab et al., 2011) of AC. Unique findings also challenge qualitative research suggesting that AC is a pleasant and positive experience for the majority patients, albeit an unusual one (Khu et al., 2010; Manchella et al., 2011; Flecther et al., 2012). Accordingly, this study suggests that previously reported negative reactions incorporating severe anxiety, discomfort and pain may be more commonplace than described before (Danks et al., 1998; Whittle et al., 2005; Goebel et al., 2010; Manchella et al., 2011). Timing of research appears pivotal because associated alterations in subjective appraisals may be influential when investigating experiences, since patients initially report minimal anxiety but subsequently, following processing of events, express more negative perceptions (Palese et al., 2008). Moreover, the diverse reports of how patients felt during AC by the neurosurgical team may reflect some patients' reluctance to report adverse intraoperative events, for fear of compromising an ongoing relationship, which they perceive as necessary for safety (Bernstein, 2003). Nevertheless, it is evident that AC represents an exceptionally stressful situation for patients, risking development of longer-term psychological sequelae (Milian et al., 2013).

Some patients in this study experienced intense anxiety and mental visualisation during and following AC, suggesting the potential for development of symptoms consistent with elements of post-traumatic stress disorder (PTSD). PTSD may occur after any traumatic event or following notification of a life-threatening diagnosis (O'Connor, Christensen, Jensen, Moller, & Zachariae, 2011). It is characterised by symptoms of re-experiencing the event, avoidance and emotional numbing, and increased physiological arousal (American Psychiatric Association, 2013). Current cognitive models of trauma emphasise the influence of personal appraisals for adapting to a potentially life-threatening experience (Ehlers & Clark, 2000). Accordingly, there may be increased susceptibility to experiencing symptoms related to PTSD should a

patient internalise AC as a threat to their life or physical integrity. Findings that patients occasionally contradicted their initial accounts surrounding the distressing nature of AC by subsequently stating it was not unpleasant may indicate avoidance of traumatic memories. A patient's report of hyper-arousal and re-experiencing adverse aspects of the procedure also replicated symptoms found in PTSD. These results endorse Millian et al. (2013) who investigated psychological sequelae in patients following awake brain surgery and found 44% reported recurrent and intrusive recollections or dreams related to AC, 20% described persistent avoidance of stimuli associated with the procedure and 62.5% stated having symptoms of increased arousal. Patients disorganised and fragmented recollections of AC in this study also resembled trauma memories previously described in clients diagnosed with PTSD (Gray & Lombardo, 2001). Findings are consistent with the report of Shobe and Kihlstrom (1997) that traumatised individuals may experience vivid sensory-laden features of the event (an implicit memory), while declarative memory containing a comprehensive narrative is often disorganised. This might also explain why the neurosurgical team described diverse views regarding a patient's ability to recall AC.

Findings emphasised the importance of considering potential long-term psychological effects when planning AC. It is recommended tentative explanation surrounding the possibility of developing postoperative emotional sequelae be offered to patients before undergoing surgery. Millian et al. (2013) affirmed study implications that preoperative preparation may be important for protecting patients against adverse psychological reactions through adaptive coping strategy development. Given current findings that AC may lead to negative psychological sequelae, the absence of objective data confirming AC as advantageous over craniotomy performed under general anaesthetic (Kirsch & Bernstein, 2012) raises significant ethical issues of beneficence and non-maleficence. Current results highlight the need for future research investigating

the longer-term psychological effects of AC and their treatment. In an attempt to process and make sense of bizarre and distressing experiences, patients utilised frames of reference, imagery and metaphors, both during and following AC, to normalise perceptions and contain apprehensive feelings. Where such experiences invoke symptoms of trauma that are enduring, imagery restructuring may offer a preliminary approach a supportive intervention for aversive psychological sequelae given its acknowledged efficacy in cognitive behavioural therapy (CBT) for reducing emotional distress associated with trauma (Holmes, Arntz, & Smucker, 2007).

Tensions of being awake

The bizarre nature of patients' AC experiences were exacerbated by a paradoxical tension of feeling caught between 'isolation from' and 'integration within' their team. Similarly, the neurosurgical team described how having an 'awake' patient invoked tensions between the coordination of inter-relating operative elements and management of client emotions to ensure collaboration with intraoperative assessments. Findings affirm Kirsch and Bernstein (2012) who found conscious patients added an element of complexity to neurosurgical procedures and support a report surrounding the intricacy between negotiating technical aspects of surgery while managing patients' emotions (Palese & Infanti, 2006). Despite these tensions, both Dropkin (2001) and Khu et al. (2010) emphasised the desirability to integrate patients within their neurosurgical team to reduce apprehension levels and enhance collaboration, thereby sustaining client autonomy and their sense of control throughout AC. However, findings identified occasions when team members required segregation from their clients in order to focus on intricate aspects of surgery, possibly promoting patient perceptions of isolation. This study supports recommendations of Rice and Warland (2013) that future research is

needed to optimise the neurosurgical teams' strategic approach to harmonise a medical model with their management of an unpredictable awake patient in an effort to optimise overall AC experience. While the study offers preliminary observations of how the team used such techniques, findings also emphasised that patients usually develop individualistic strategies to cope with periods of 'isolation from' or 'integration within' the neurosurgical team. Accordingly, perspectives from both parties will require consideration to enhance current clinical practice.

The management of intraoperative emotion

Both patients and neurosurgical team members reported feelings of stress and anxiety during AC, arising from the previously described tensions and other personal elements, with parties requiring different management strategies.

Patients experienced significant self-induced pressure and anxiety to perform optimally for the neurosurgical team which was exacerbated by uncertainty of their role. Results confirmed previous literature describing how patients felt directly responsible for AC outcome, perceiving control of emotions as crucial for effective collaboration with team members (Palese et al., 2008). Accordingly, patients adopted a range of specific approaches to contain psychological reactions, consistent with Fletcher et al. (2012). A predominant strategy was placement of complete faith in the expertise of their neurosurgical team. Trust was enhanced through effective intraoperative communication, including positive informational feedback. Findings endorse previous studies that intraoperative communication throughout AC provided reassurance, reduced anxiety and promoted self-control (Khu et al., 2010; Fletcher et al., 2012). The importance of reassurance during AC was also recognised by the neurosurgical team, consistent with Palese and Infanti (2006) who reported how nurses attempted to comfort patients by engaging in occasional conversation. In accordance with attachment theory, the neurosurgical team may reassure patients of their ability to provide safety by offering expert knowledge through periodic informational updates (Griffin & Bartholomew, 1994). However, study findings endorse Salmon et al. (2011) who counselled that the amount, timing and content of information offered must be based on patient preference to avoid unintentionally focusing attention towards unwanted surgical aspects.

Patients also described utilising other methods of coping to manage their emotions, including a mental checklist of operative stages, internal and external avoidance and distraction techniques, stoicism and humour. The neurosurgical team also reported facilitating patients' usage of some distraction and reorientation approaches. Fletcher et al. (2012) and Milian et al. (2013) explained how distraction or avoidance techniques were used effectively by both patients and team members for reducing anxiety during AC. Results are consistent with studies conducted on awake cataract and spinal surgeries that advocated distraction techniques including intraoperative music (Lepage, Drolet, Girard, Grenier, & DeGragne, 2001) and viewing video (Man et al., 2003) to manage patients' intraoperative psychological reactions. Appropriateness of humour and conversation during AC has also been assessed by Kirsch and Bernstein (2012) who emphasised the importance of patient preferences. There is a paucity of literature exploring usage of coping mechanisms during AC or other awake procedures, highlighting the need for future research to determine effective strategies. Since most patient strategies arise within the context of the neurosurgical team, focused investigation surrounding how practitioners may facilitate optimal coping for prospective patients is needed, especially considering reported uncertainty regarding how best to support them.

Members of the neurosurgical team also reported experiencing significant levels of stress and anxiety throughout AC. Stress arose predominantly through a heightened concern of causing harm associated with restrained objectivity and tension surrounding controlled coordination of inter-relating operative elements while being unable to predict patient reactions. Other intraoperative stressors included equipment problems, inappropriate patient positioning and distractions, affirming previous research by Arora et al. (2009). Findings are surprising given surgical communities seldom acknowledge the pressure associated with operations, perhaps because emphasis on leadership and self-confidence means stress is perceived as a sign of weakness or failure (Moorth, Munz, Dosis, Bann, & Darzi, 2003). Intraoperative stress has been reported to compromise judgment, decision making and communication (Arora et al., 2010), and may account for errors and poor surgical outcomes (Heimreich, 2000). Surgeons still do not receive explicit training on managing stress, but have been reported by Arora et al. (2009) to develop idiosyncratic coping strategies and, in agreement with current findings, utilise predominant approaches of 'cognitive self-control' and pre-surgical planning to maintain composure. Unique findings confirmed strategies were facilitated when an informed and experienced team managed numerous operative elements while communicating appropriately.

Within health care literature, anaesthetists have pioneered stress-management training (Gaba, Fish, & Howard, 1994) and further research is necessary to ascertain whether similar programmes would benefit other members of the neurosurgical team. Arora et al. (2009) advocates key intervention components should incorporate: (1) recognising stress in oneself and in others, (2) experiencing the impact of stress on performance, (3) teaching effective coping strategies, (4) providing opportunities to practice what has been taught in a safe, simulation-based environment, and (5) offering

feedback from peers. The psychological impact of ongoing stress and how to support neurosurgical teams appropriately requires further investigation.

Maintaining control of numerous inter-relating operative elements, within the theatre environment, was pivotal for safety. Findings that clearly defined roles, crossmonitoring, appropriate theatre conduct, tailored communication and familiarity with neurosurgical strategy optimised control confirms the report of Palese and Infanti (2006) that appropriate communication and avoidance of organisational or technical difficulties was best enabled by experienced AC teams. Wider health literature also highlights the importance of effective teamwork to ensure patient safety within the operating room (Paige et al., 2009). Similar to study results, competencies associated with optimal teamwork are reported to encompass situational awareness, role clarity, close-loop communication and feedback, cross-monitoring, team orientation and shared vision (Baker, Day, Salas, 2006). Analysis of adverse events in healthcare revealed underlying causes originate predominantly from behavioural failures, particularly communication breakdown, rather than lack of technical expertise (Bogner, 2004). Current findings provide preliminary indications of non-technical skills that enhance teamwork and control. New personnel to AC should be instructed about appropriate behaviour and conduct in the operating room (Kirsch & Bernstein, 2012). In particular, consideration must be given to the amount and substance of intraoperative discussion, since patients' emotional state may be altered by insensitive comments (Zener & Bernstein, 2011). Improving a 'shared mental model' that contains the aims and clinical priorities of team members and how they interact may also enhance communication (Brown, 2010). The World Health Organisation (WHO) advocates team meetings incorporating a 'surgical checklist' which allows identification and elimination of potential errors before surgery commences (WHO, 2009). Accordingly, development and implementation of a structured briefing protocol containing these aforementioned

elements may promote a team-centred approach, enabling practitioners to adopt essential competencies for appropriate behaviour during AC (Paige et al., 2009).

A strong emotional attachment

Patients felt compelled to form strong emotional attachment with a specific team member, enabling containment and a sense of safety when feeling overwhelmed. Similarly, the neurosurgical team regarded allocation of a dedicated practitioner as important to alleviate aforementioned tensions and provide patients with reassurance, thereby maintaining control. As both parties shared the experience of proceeding through intraoperative tasks together, a highly empathic patient-practitioner relationship developed within the emotionally-intense context of AC. In accordance with study findings, the significance of an empathic patient-practitioner relationship in ensuring a positive AC experience is alluded to by patients (Fletcher et al., 2012) and professionals (Palese & Infanti, 2006), consistent with wider literature surrounding patientneurosurgical team relations (Chibnall & Tait, 1995; Axelrod & DorrGoold., 2010). The patient-midwife relationship probably most closely replicates patient-practitioner attachment formed during AC and is considered pivotal in women's experiences of labour, often described as a friendship, illustrating its emphatic nature (Larkin, Begley, & Devane, 2010). Similar to study results, this association is remembered over time (Bluff & Holloway, 1994) and without such companionship, women felt dissatisfied with treatment experiences (Fraser, 1999).

Surprisingly, there is limited literature regarding theoretical explanation surrounding how strong attachments are formed during awake procedures that are potentially traumatic or emotionally overwhelming. Consistent with study results, attachment theory suggests that during overwhelming operative situations, by seeking close proximity to practitioners, patients may obtain a sense of safety (Griffin & Bartholomew, 1994). A unique finding of this attachment was that practitioners became emotionally involved and suggests relationship formation extended beyond conscientious execution of their contracted role, refuting previous conclusions of Salmon et al. (2011). Study findings endorse Palese and Infanti (2006) that optimal relationships were established when practitioners extended beyond this contracted role and included overt displays of closeness, physical touch, empathy and genuine care. Further research into what motivates and assists development of these extended caring behaviours is recommended, including investigation of altruism theory which suggests consideration of practitioner attitudes and values is important (Arnold & Ster, 2006).

Findings recommend the assignment of a familiar team member to provide constant support and intercede for patients as prerequisite for a positive AC experience in an effort to protect against negative psychological sequelae, consistent with Milian et al. (2013). Knifed, July and Bernstein (2008) also suggest how introducing and explaining the role of each team member to the patient preoperatively may optimise trusting relationships, providing a sense of familiarity throughout AC. Engaging in empathic care may leave clinicians vulnerable to significant distress, especially when bearing witness to patients' experiences of trauma (Showalter, 2010). Accordingly, research is required surrounding the emotional impact on neurosurgical team members who become emotionally close to distressed patients. Rice and Warland (2013) recommend support from colleagues, opportunities for reflection and debriefing, and counselling, may provide protection against adverse reactions but further research surrounding incidence of distress and efficacious interventions within surgical communities is warranted.

Postoperative

Biopsychosocial Adjustment

Pre-discharge

Patients faced considerable emotional and physical adjustment following sudden realisation of what they had just experienced, awareness of postoperative deficits or an insight that AC had not been curative while the neurosurgical team exhibited varying appreciation of these issues.

Patients' overriding loss of control and hope were characterised by diverse psychological reactions identified in the study which have been described previously in BT populations. Realisation of diagnosis and neurological deficits are reported to evoke psychological reactions of shock, frustration, depression and anger postoperatively (Palese et al., 2008; Goebel et al., 2010; Manchella et al., 2011; Lovely et al., 2013). Such responses share attributes similar to initial stages of grief and may be adaptive by protecting against overwhelming suffering (Koopman & Schweitzer, 1999). However, if sustained over extended periods, these types of reaction could become maladaptive, preventing appropriate adjustment to circumstances (Travis, Pawa, LeBlanc, & Rogers, 2011). This is consistent with Ownsworth, Little, Turner, Hawkes and Shum (2008) who reported clinically significant levels of postoperative anxiety and depression in one-third of BT patients. Unique to this study was confirmation that some members of the neurosurgical team were aware of the aforementioned issues although a physical focus on recovery appeared to compromise further exploration.

Ownsworth et al.'s (2011) report that many patients appeared unprepared about what to expect post-surgery are consistent with current findings that patients often had

unrealistic hope and expectations despite clear warnings from their team about possible neurological impairment and guarded prognosis. This contrasts Rosenblum et al.'s (2009) suggestion that lack of preoperative communication with neurosurgical team members or their reluctance to predict specific outcomes were contributory. Consistent with study findings, Taillibert et al. (2004) highlighted considerable variation in patients' receptiveness and ability to recall conversations prior to treatment. However, current findings also suggest patients may have filtered out unfavourable warnings in favour of the hope of a good outcome, thereby facilitating them to undergo AC. This contrast between anticipated and experienced outcomes likely contributed to patients' aversive psychological reactions, as reported by Johnson (1973).

The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) provides a useful theoretical perspective when considering the early postoperative impact of AC. It suggests a dialectical and oscillating process in which either an illness-in-the-foreground or wellness-in-the-foreground perspective predominates. Threats to control that exceed an individual's tolerance threshold are believed to shift perspectives from wellness to illness in the foreground, characterised by focusing on sickness, loss or burden (Raleigh, 1992). Accordingly, the stark realisation of unexpected neurological deficits and their prognosis that emphasised powerlessness and losing control would direct patient perceptions towards illness from a prior belief that they would be cured.

Current results emphasise the importance of avoiding creation of false hope or expectation consistent with Langbecker, Janda, & Yates (2013) who considered appropriate communication as an essential skill for team members involved in BT patients care. The difficulty of balancing information provision and fostering a realistic sense of hope is reported in palliative care settings (Clayton, Butow, Arnold, & Tattersall, 2005) but little advice is available to guide practitioners who are trying to weigh the need to inform their patients without compromising consent to AC.

Accordingly, professionals need to consider appropriate methods for delivering information based on patient preference and its reiteration post-treatment. This may be facilitated by further research exploring individual patient's illness perspectives (Keeling, Bambrough, & Simpson, 2013).

Post-discharge

Patients described adjustment as an ongoing individualistic process, encompassing rehabilitation of deficits, home integration and further treatment, being influenced by patients' efforts to regain a sense of normality and control over their lives, consistent with Ownsworth et al. (2011) and Lovely et al. (2013). In contrast, although some members of the neurosurgical team recognised this continuing process, they appeared to have limited resources to address patients' adjustment concerns.

Constraints on patients' ability to undergo substantive adjustment are to be anticipated given Lidstone et al. (2003) report that patients with BT have the highest levels of fatigue, cognitive difficulties and activity restrictions of all cancer groups. Despite paucity of BT specific research in this area, and consistent with study findings, Adelbratt and Strang (2000) emphasise that patients face the dilemma of balancing uncertainty over their future with hope of regaining meaningful life. When confronted with uncertainty and existential issues, patients in this study adopted an attitude of acknowledging the seriousness of their prognosis while trying to derive positive meaning from their experiences in an effort to maintain hope. Strang and Strang (2001) advocated a 'sense of coherence' framework offering a preliminary approach for understanding how patients' adjust to BT. Promotion of hope centred around restoring meaningfulness in life by redefining roles and reappraising personal values. Study findings concur with BT research (Sterckx et al., 2015) and wider cancer literature

(Nixon, Narayanasamy, & Penny, 2013) that having a sense of meaning is an important resource from which patients draw hope and strength. The adjustment process altered patients' self-identity and independence, consistent with Lovely et al. (2013), but with a unique finding that this involved both loss and positive growth. Anderson-Shaw, Baslet, and Villano (2010) report that loss of self-identity is rarely acknowledged by practitioners, consistent with results that team members failed to recognise these alterations. Moreover, current literature does not offer a clinical tool for BT populations to effectively assist practitioners in assessing the concept of self-identity (Anderson-Shaw et al., 2010).

The Shifting Perspectives Model of Chronic Illness (Paterson, 2001) provides a useful theoretical perspective and endorses findings that returning to a wellness-in-the-foreground perspective requires adaptation to circumstances that provoked an illness focus. Accordingly, individuals attempt to create consonance between self-identity and identity shaped by illness (Fife, 1994), promoting a renewed appreciation of life and transformed identity. While study patients derived hope and meaning by maintaining a wellness-in-the-foreground perspective, ongoing treatment and management of BT often required them to focus on their illness. Therefore, recognition that BT was a fact of life while rejecting its significance became a constant challenge for patients, viewing their new world and identity as encompassing both positive and negative domains.

Ongoing Support

Both patients and members of the neurosurgical team considered ongoing social support, tailored to clients' idiosyncratic preferences, pivotal for development of hope and positive adjustment. The significance of social support is recognised increasingly in chronic health conditions (Martire, Lustig, Schulz, Miller, & Helgeson, 2004) and encompasses informational, psychological and tangible assistance from formal and informal systems, access to services and rehabilitation (Ownsworth et al., 2011). Continuing care allowed study patients accessibility to trusted team members who communicated information for concerns surrounding diagnosis, additional treatment and future uncertainties. Provision of information, accessibility to practitioners and continuing healthy relationships with trusted team members are reported as crucial for adjustment (Strang & Strang, 2001; Lovely et al., 2013; Sterckx et al., 2015). However, current findings concur with Edvardson and Ahlstrom (2005) that patient preferences vary surrounding the nature of support and the amount, type, and content of information provided. Nevertheless, patients' hope becomes established through continued trusting relationships, especially during initial periods of hopelessness. Bernardo (2010) emphasises the importance of such support to allow timely development of independence and autonomy, shifting anchoring of hope from external to internal.

While both groups recognised the importance of ongoing support, postoperative care, informed by a medical model, was focused primarily on aspects of physical recovery, thereby constraining and compromising continued optimal relationships. Consistent with study findings, Strang and Strang (2001) reported BT patients' satisfaction with procedural and physical aspects of their care but felt the emotional impact of their illness was often overlooked, with poor team understanding of existential issues, lack of knowledge, avoidance through anxiety and time restraints being contributory. Team members also appeared reluctant to address adjustment concerns for fear of invoking adverse reactions consistent with O'Donnell (2005). Results also agree with Ray et al. (1986) who reported that most surgeons do not consider communication surrounding adjustment difficulties as part of their contracted role. This may explain the recommendations for patients to receive enhanced

postoperative psychological care and more comprehensive information about available support (Lepola et al., 2001; Khu et al., 2010).

Results imply that a medical model alone cannot adequately accommodate the diverse and continuing postoperative support needs of patients with BT. The importance of ongoing holistic and specialist care has been endorsed within UK healthcare policies and government initiatives (House of Commons Health Committee, 2005). Langbecker et al. (2013) considered treatment informed solely by a medical model of care resulted in poor communication, continuity and coordination. Integration of holistic care informed by a biopsychosocial model has been advocated to improve provision of consistent, timely and appropriate information, tailored to patients' needs, across BT disease trajectory (Ownsworth et al., 2009; Walsh et al., 2011). It appears access to evidence-based psychological support is imperative across the adjustment continuum, with particular focus on holistic and relationship-centred interventions and maintaining support structures (Rosenblum et al., 2009). However, no published control trials for such interventions exist within BT populations, emphasising the need for future research (Kangas et al., 2012).

Despite limited research considering how such an approach might be developed, Hutchison, Steginga, and Dunn (2006) accentuated how any supportive care approach must include accessibility of appropriate information about a patients' BT and its treatment with early screening and ongoing management of both psychological distress and neurological deficits. Given limited resources, the authors also recommended a triage approach for BT patients to define need-dependent levels of support, with care adjusted over time as appropriate, based on previous models of cancer service delivery. Such patients have a relatively poor prognosis and Taillibert et al. (2004) emphasised the importance of encouraging them to discuss their fears and prepare for the future, consistent with palliative care guidelines. Consistent with study findings, Adelbratt & Strang (2000) highlighted how relevant professionals require specialist training surrounding communication of appropriate information and provision of support related to existential issues for BT patients.

Strengths and Limitations

A major strength of the current study was its unique incorporation of both patient and neurosurgical team groups which allowed, for the first time, an in-depth two-dimensional exploration surrounding perioperative interactions, before, during and after AC. Multicentre recruitment for both groups also appeared advantageous and ensured patients' reports reflected a range of care teams while highlighting the diversity of approaches employed by neurosurgical departments. Adequate sample sizes for each group provided sufficient high-quality rich data acceptable for IPA analysis (Smith et al., 2009) and no participants withdrew from the study. However, as is common with qualitative methodologies employing small numbers, findings are not intended to be generalised, since IPA aims to examine individual experiences rather than make broad generalisations (Smith & Osborn, 2008). Nevertheless, findings extend considerably the small-evidence base surrounding patients' and practitioners' experiences of AC.

Smith et al. (2009) emphasised the importance of sample homogeneity when using IPA to ensure that convergence and divergence may be examined in detail. A strength was that the patient group selected had all undergone AC for BT within the previous two years reflecting relatively good homogeneity. In contrast, the neurosurgical team group was more heterogeneous, and a study limitation, since it included a speech and language therapist, clinical neuropsychologists and consultant neurosurgeons. The rationale for selecting a diverse group of healthcare professionals was based primarily on the absence of any literature using IPA to suggest perceptions

might vary according to discipline, all had potential to influence a patient's experiences, and because the study was exploratory. All participants within the neurosurgical team group had direct patient contact throughout the perioperative period, providing a degree of homogeneity. Furthermore, the themes raised by different disciplines proved homogenous and embodied similar perceptions concordant with the qualitative report of Palese and Infanti (2006) who examined nurses' experiences of AC.

A possible limitation of the study arises from using a retrospective approach for a condition which has a progressive and variable nature where perceptions of AC, BT and its effects may have altered since the operation. Palese et al. (2008) reported the significant influence of research timing on findings after AC. In an attempt to minimise this, patients were only included if they had undergo AC within the previous two years. A prospective qualitative approach was considered when designing the study but rejected given reported limitations of a superficial split in experiences between pre and post-AC interviews where less information was shared preoperatively consistent with minimal processing due to limited time from diagnosis to surgery (Palese et al., 2008; Khu et al., 2010).

Another constraint of study design arises from the risk of recruitment and sampling bias invoked following a postal invitation leading to 'opted in' participants who were prepared or willing to discuss their AC experiences. Accordingly, recruitment methodology and exclusion criteria may have underrepresented individuals less willing to discuss experiences of AC, or those unable to participate because of neurological deficits or mental health problems. No attempts were made to ascertain why potential participants did not respond to study invitation. Alternative methods of recruitment such as directly approaching patients in clinic or team members during supervision groups were not considered feasible given the study timescale. Ethnicity was not recorded limiting any considerations regarding possible cultural influences over how participants viewed AC experiences despite the reported impact of ethnicity on perceptions of disease and treatment by de Boer, Mula, & Sander (2008).

Another potential limitation relates to the researcher's subjective assumptions and experiences of reality, influenced through training as a clinical psychologist informed by a holistic biopsychosocial model, which may have impacted on data interpretation, questioning credibility, reliability and validity of findings. Although total researcher objectivity is unachievable, it is emphasised that an integral component of IPA analysis includes researcher subjectivity. In order to address this subjective doublehermeneutic, the researcher kept a reflective diary acknowledging subjective assumptions, utilised a peer IPA research group and undertook regular supervision with two clinical psychologists to inform insights. In addition, the researcher ensured themes identified were grounded in exact verbal accounts and evaluated with participants whether their experiences had been well represented.

Clinical Recommendations

Although patients' AC experiences appeared more stressful than has been reported previously, it was recognised that these were improved by positive relationships with neurosurgical team members. Accordingly, it is recommended that a dedicated professional from the neurosurgical team is assigned to each patient throughout the perioperative period of AC to provide information and support. Ongoing training surrounding how to establish optimal patient-practitioner relationships, focusing on the usage of contextually appropriate communication behaviours to facilitate emotional containment, may be beneficial. Development of a comprehensive preoperative education curriculum could also assist a practitioner in both relationship development and patient preparation for AC though adaptive information sharing. This offers the potential to protect patients against negative psychological reactions by strengthening efficacious coping strategies. Moreover, continued involvement of a dedicated team member postoperatively may enhance identification of, and appropriate support for, patients' adjustment concerns and possible negative psychological sequelae resultant from AC. Given the diverse reactions of patients and limited hospital resources, establishment of a triage service appears most appropriate to provide holistic, relationship-centred interventions based on patients' biopsychosocial needs (Hutchison et al., 2006).

As members of the neurosurgical team employed disparate and subjective criteria when selecting patients for AC, development of comprehensive suitability guidelines is advised. Moreover, given informed and experienced teams best facilitated the AC procedure, it is recommended that specialist training be offered surrounding the essential competencies for acceptable behaviour within the operating room. Enhancement of this practice may also be assisted by the development and implementation of a specific structured team-briefing protocol before undertaking AC. Finally, the ongoing impact of stress on neurosurgical team members requires greater recognition and it is recommended that avenues of appropriate support be established.

Conclusions

This study adds to current understanding of patient and neurosurgical team experiences of AC, being the first to explore both parties' perspectives on relationships and communication throughout the preoperative, intraoperative and postoperative periods. It emerged that establishment and building of relationships, hope and trust was
crucial for optimising AC experience and enabling coping, requiring contextually appropriate communication behaviours at each operative stage based on patient preferences, levels of apprehension and ability to process information.

Patients found their AC experiences more stressful than previously reported, raising concerns over potential development of long-term psychological sequelae and faced considerable psychosocial adjustment, sometimes constrained by lack of resources and emphasis on a medical model of service. It was felt that preoperative preparation was important for protecting patients against adverse psychological sequelae, through adaptive coping strategy development, emphasising the need for development of a more comprehensive preoperative education curriculum to assist preparation for AC. Assignment of a dedicated team member is recommended to provide constant support and intercede for patients to optimise AC experience and protect against negative psychological reactions. Enhancement of psychological assistance that focuses on holistic and relationship-centred interventions and improved access to relevant information about other support services is recommended.

Members of the neurosurgical team appeared to employ disparate and subjective criteria when considering a patient's suitability for AC. The neurosurgical team reported significant levels of stress during AC and optimisation of both parties' experiences was best achieved when an experienced team adopted an approach that harmonised a medical model with strategic management of unpredictable awake patients. It is considered that comprehensive guidelines to assist neurosurgeons when considering patient suitability for AC require development. It was felt that professionals would benefit from specialist training surrounding timely communication of appropriate information, essential competencies for acceptable behaviour and other methods of providing support for patients, requiring re-evaluation of their contracted role. The psychological impact of ongoing stress and how to support teams effectively requires

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further investigation and it is recommended that a structured team-briefing protocol be developed and implemented before undertaking AC.

Comprehensive study findings advocate coordination of patient-centred holistic care informed by a biopsychosocial model to optimise relationship building and team performance given the limitations of a medical model to meet diverse support needs of AC patients across the BT disease and treatment trajectory.

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Appendices

Appendix A – Submission guidelines for Brain Impairment

CAMBRIDGE Instructions for Contributors

Brain Impairment

These instructions follow the latest edition of the Publication Manual of the American Psychological Association (http://www.apastyle.org/). Authors of research manuscripts are strongly encouraged to follow relevant reporting guidelines as outlined in the special editorial: Use of Reporting Guidelines in Scientific Writing: PRISMA, CONSORT, STROBE, STARD and Other Resources, Brain Impairment, 12, 1–21 (http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=849539 0&fulltextType=ED&fileId=S144396460002217). A statement confirming ethics approval should be included in all research manuscripts.

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If you encounter any problems or have any queries about submitting your paper please contact the Editors-in-Chief:

Jennifer Fleming E-mail: j.fleming@uq.edu.au

or

Grahame Simpson E-mail: Grahame.Simpson@sswahs.nsw.gov.au

All articles are refereed. Papers submitted to the journal must not have been published previously or submitted for publication to any other journal and must represent original work.

Manuscript Preparation

Manuscripts must be presented double spaced in a clear, readable typeface (Times preferred), in an A4-size document with 3 cm margins. Number all pages except the figures, beginning with the first page. Your submission should have a separate title page bearing the name(s) and affiliation(s) of the contributing author(s), and an abstract of no more than 200 words with keywords typed on a separate page. An e-mail address and/or fax/telephone numbers are required for contact purposes and should be stated following the corresponding author's address in a footnote on the title page.²

Headings

Provide headings that subdivide the paper into its key areas. Reports of empirical studies will generally follow a sequence of headings, including method, results and discussion. Review, theoretical, case study and other papers need not follow such a format but should provide a logical structure and appropriate section headings.

² Please note that the formatting of both the Systematic Literature Review and Empirical Paper is different to these guidelines due to binding regulations for the thesis.

Style

The written paper should be logical, economical and precise in structure and use of language.

Tables

Reserve tables for important data directly related to the content of the paper. A wellconstructed table should enable data to be isolated from the text and presented in a way that enables the reader to quickly see patterns and relationships of the data not readily discernible in the text. Use brief but explanatory table titles. The table title is placed at the top of the table. Include each table on a separate sheet. When constructing tables use tabs to space your columns as this will make it much easier to typeset the table in the text.

Figures

Figures should be prepared to the correct size (max. width up to 120 mm) and each one supplied as an individual file, separate to the manuscript Word file. Include placement instructions in the Word document, such as 'Insert Figure 1 here'. The figure title is placed at the bottom of the figure. Prior to sending artwork, the separate files of figures, graphs, illustrations, should be printed by the author to test that the fonts have been embedded correctly and there is no distortion in the artwork as any such faults cannot be corrected by the publisher. If you request colour figures in the printed version, you will be contacted by CCC-Rightslink who are acting on our behalf to collect Author Charges. Please follow their instructions in order to avoid any delay in the publication of your article.

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References and citations should follow the APA format. Some examples to assist you are provided below.

Citations in text

For a single author: In a recent review, Smith (1992) suggested that ... A recent review (Smith, 1992) suggested that ... In 1992, Smith suggested that ...

For two authors: In a recent review, Smith and Watson (1992) suggested that ... A recent review (Smith &Watson, 1992) suggested that ... In 1992, Smith and Watson suggested that...

When a work has three, four, or five authors: Cite all authors the first time the reference occurs; thereafter, the name of the first author followed by et al. (e.g., Smith et al., 1991).

The full list of authors must be cited in the list of references at the end of the paper. If use of the 'et al.' format gives rise to confusion, with another work of the same year and with the same first author, the references should be differentiated by the use of alphabet sequence following the publication year (e.g., Smith et al., 1991a; Smith et al., 1991b).

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General: Within a paragraph the year need not be repeated in subsequent citations of the same study provided the study cannot be confused with other studies cited in the

paper. When citing several studies within the same set of parentheses, the following format should be adhered to '... several studies (Brooks, 1974a, 1974b; Cairns et al., 1992; Miller, in press; Smith, 1992; Tarter et al., 1985, 1987; Watson & Smith, 1990) have reported that ...'.

Reference List

Chapter in an edited book: Heilman, K.M., Watson, R. T., & Valenstein, E. (1985). Neglect and related disorders. In K.M. Heilman & Valenstein (Eds.), Clinical neuropsychology (2nd ed., pp. 243-293), New York: Oxford University Press.

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Unpublished paper presented at a conference: Walsh, K.W. (1986, August). Bridging the gaps in clinical neuropsychology: The applied scientist model. Paper presented at the 21st Annual Conference of the Australian Psychological Society, James Cook University, Townsville, Queensland.

Theses: Author, (Year). Title. Type of thesis, Institution, Location of Institution.

General: Papers in the Reference List should be listed alphabetically by first author, and then by date. Single author entries precede multiple author entries beginning with the same surname. References with the same first author and different second or third authors are arranged alphabetically by the surname of the second author, and so on.

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Acknowledgements

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(Revised 17/02/2015)

	Study details	Reason for
		exclusion
1	Baumann, I., Polligkeit, J., Blumenstock, G., Mauz, P. S.,	The HRQofL
	Zalaman, I., & Maassen, M. (2005). Quality of life after	measurement was
	unilateral acoustic neuroma surgery via middle cranial	not validated in brain
	fossa approach. Acta Oto-Laryngologica, 125(6), 585-	tumour populations
	591.	
2	Betchen, S. A., Walsh, J., & Post, K. D. (2003). Self-	The HRQofL
	assessed quality of life after acoustic neuroma surgery.	measurement was
	Journal of Neurosurgery, 99(5), 818-823.	not validated in brain
		tumour populations
3	Boele, F. W., Douw, L., Reijneveld, J. C., Robben, R.,	The HRQofL
	Taphoorn, M. J. B., Aaronson, N. K,Klein, M. (2015).	measurement was
	Health-related quality of life in stable, long-term	not validated in brain
	survivors of low-grade glioma. Journal of Clinical	tumour populations
	Oncology, 33, 1023-1029.	
4	Bosma, I., Reijneveld, J. C., Douw, L., Vos, M. J.,	The study did not
	Postma, T. J., Aaronson, N.K.,Klein, M. (2009).	specifically examine
	Health-related quality of life of long-term high-grade	factors influencing
	glioma survivors. Journal of Neuro-Oncology, 11(1), 51-	HRQofL
	58.	
5	Brooker, J. E., Fletcher, J. M., Dally, M. J., Briggs, R. J.	The HRQofL
	S., Cousins, V. C., Smee, R. I.,Burney, S. (2010).	measurement was
	Quality of life among acoustic neuroma patients managed	

	by microsurgery, radiation, or observation. Otology and	not validated in brain
	Neurotology, 31(6), 977-984.	tumour populations
6	Bunevicius, A., Tamasauskas, S., Deltuva, V.,	The HRQofL
	Tamasauskas, A., Radziunas, A., & Bunevicius, R.	measurement was
	(2014). Predictors of health-related quality of life in	not validated in brain
	neurosurgical brain tumour patients: focus on patient-	tumour populations
	centred perspective. Acta Neurochirurgica, 156(2), 367-	
	374.	
7	Cheng, J., Liu, B., Zhang, X., Lin, W., Zhang, Y., Liu,	The HRQofL
	W.,Yin, H. (2010). Health-related quality of life in	measurement was
	glioma patients in China. BMC Cancer, 10, 305.	not validated in brain
		tumour populations
8	Giovagnoli, A. R. (1999). Quality of life in patients with	The HRQofL
	stable disease after surgery, radiotherapy, and	measurement was
	chemotherapy for malignant brain tumour. Journal of	not validated in brain
	Neurology, Neurosurgery, and Psychiatry, 67(3), 358-	tumour populations
	363.	
9	Giovagnoli, A. R., Silvani, A., Colombo, E., & Bolardi,	The HRQofL
	A. (2005). Facets and determinants of quality of life in	measurement was
	patients with recurrent high grade glioma. Journal of	not validated in brain
	Neurology, Neurosurgery, and Psychiatry, 76(4), 562-	tumour populations
	568.	
10	Giovagnoli, A. R., Tamburini, M., & Boiardi, A. (1996).	The HRQofL
	Quality of life in brain tumour patients. Journal of	measurement was
	Neuro-Oncology, 30(1), 71-80.	not validated in brain
		tumour populations

11	Habets, E. J. J., Taphoorn, M. J. B., Nederend, S., Klein,	The study did not
	M., Delgadillo, D., Hoang-Xuan, K.,Reijneveld, J. C.	specifically examine
	(2014). Health-related quality of life and cognitive	factors influencing
	functioning in long-term anaplastic oligodendroglioma	HRQofL
	and oligoastrocytoma survivors. Journal of Neuro-	
	Oncology, 116(1), 1, 161-168.	
12	Halkett, G. K. B., Lobb, E. A., Rogers, M., ., Shaw, T.,	The HRQofL
	Long, A. P., Wheeler, H. R., & Nowak, A. K. (2015).	measurement was
	Predictors of distress and poorer quality of life in high	not validated in brain
	grade glioma patients. Patient Education and	tumour populations
	Counselling, 98, 525-532.	
13	Heimans, J. J., & Taphoorn, M. J. B. (2002). Impact of	The paper was a
	brain tumour treatment on quality of life. Journal of	review article
	Neurology, 249(8), 955-960.	
14	Jakola, A. S., Gulati, M., Gulati, S., & Solheim, O.	The HRQofL
	(2012). The influence of surgery on quality of life in	measurement was
	patients with intracranial meningiomas: a prospective	not validated in brain
	study. Journal of Neuro-Oncology, 110(1), 137-144.	tumour populations
15	Jakola, A. S., Unsgård, G., & Solheim, O. (2011).	The HRQofL
	Quality of life in patients with intracranial gliomas: the	measurement was
	impact of modern image-guided surgery. Journal of	not validated in brain
	Neurosurgery, 114(6), 1622-1630.	tumour populations
16	Liu, R., Solheim, K., Polley, M., Lamborn, K. R., Page,	The study did not
	M., Fedoroff, A.,Chang, S. M. (2009). Quality of life	specifically examine
	in low-grade glioma patients receiving temozolomide.	factors influencing
	Journal of Neuro-Oncology, 11(1), 59-68.	HRQofL

17	Mainio, A., Hakko, H., Niemelä, A., Koivukangas, J.,	The HRQofL
	Räsänen, P. (2006). Gender difference in relation to	measurement was
	depression and quality of life among patients with a	not validated in brain
	primary brain tumour. European Psychiatry, 21(3), 194-	tumour populations
	199.	
18	Martin, H. C., Sethi, J., Lang, D., Neil-Dwyer, G.,	The HRQofL
	Lutman, M. E., & Yardley, L. (2001). Patient-assessed	measurement was
	outcomes after excision of acoustic neuroma:	not validated in brain
	postoperative symptoms and quality of life. Journal of	tumour populations
	Neurosurgery, 94(2), 211-216.	
19	Miao, Y., Lu, X., Qiu, Y., Jiang, J., & Lin, Y. (2010). A	Participants below
	multivariate analysis of prognostic factors for health-	the age of 18 were
	related quality of life in patients with surgically managed	included
	meningioma. Journal of Clinical Neuroscience, 17(4),	
	446-449.	
20	Minniti, G., Scaringi, C., Baldoni, A., Lanzetta, G., De	The study was a
	Sanctis, V., Esposito, V., & Enrici, R. M. (2013). Health-	clinical trial
	related quality of life in elderly patients with newly	
	diagnosed glioblastoma treated with short-course	
	radiation therapy plus concomitant and adjuvant	
	temozolomide. International Journal of Radiation	
	Oncology, Biology, Physics, 86(2), 285-291.	
21	Nikolopoulos, T. P., Johnson, I., & O'Donoghue, G. M.	The HRQofL
	(1998). Quality of life after acoustic neuroma surgery.	measurement was
	The Laryngoscope, 108(9), 1382-1385.	not validated in brain
		tumour populations

22	Osoba, D., Aaronson, N. K., Muller, M., Sneeuw, K.,	The focus was on the
	Hsu, M. A., Yung, W. K.,Newlands, E. (1997). Effect	development and
	of neurological dysfunction on health-related quality of	validation of a
	life in patients with high-grade glioma. Journal of Neuro-	HRQofL
	Oncology, 34(3), 263-278.	questionnaire
23	Ownsworth, T., Dwan, T., Chambers, S., Walker, D. G.,	The HRQofL
	& Shum, D. H. K. (2014). The moderating effect of	measurement was
	estimated pre-morbid IQ on the relationship between	not validated in brain
	neuropsychological status and subjective well-being after	tumour populations
	brain tumour. Journal of Psychosomatic Research, 76(3),	
	257-260.	
24	Pelletier, G., Verhoef, M. J., Khatri, N., & Hagen, N.	The HRQofL
	(2002). Quality of life in brain tumour patients: the	measurement was
	relative contributions of depression, fatigue, emotional	not validated in brain
	distress, and existential issues. Journal of Neuro-	tumour populations
	Oncology, 57(1), 41-49.	
25	Ruge, M. I., Ilmberger, J., Tonn, J. C., & Kreth, F. W.	The HRQofL
	(2011). Health-related quality of life and cognitive	measurement was
	functioning in adult patients with supratentorial WHO	not validated in brain
	grade II glioma: status prior to therapy. Journal of	tumour populations
	Neuro-Oncology, 103(1), 129-136.	
26	Salander, P., & Bergenheim, A. T. (2000). How was life	The focus was on the
	after treatment of a malignant brain tumour? Social	development and
	Science & Medicine, 51(4), 589-598.	validation of a
		HRQofL
		questionnaire

27	Salo, J., Niemelä, A., Joukamaa, M., & Koivukangas, J,	The HRQofL
	(2002). Effect of brain tumour laterality on patients'	measurement was
	perceived quality of life. Journal of Neurology,	not validated in brain
	Neurosurgery, and Psychiatry, 72(3), 373-377.	tumour populations
28	van Nieuwenhuiz, D., Ambachtsheer, N., Heimans, J. J.,	The HRQofL
	Reijneveld, J. C., Peerdeman, S. M., & Klein, M. (2013).	measurement was
	Neurocognitive functioning and health-related quality of	not validated in brain
	life in patients with radiologically suspected	tumour populations
	meningiomas. Journal of Neuro-Oncology, 113(3), 433-	
	440.	
29	Waagemans, M. L., van Nieuwenhuiz, D., Dijkstra, M.,	The HRQofL
	Wumkes, M., Dirven, C. M. F., Leenstra, S.,Stalpers,	measurement was
	L. J. A. (2011). Long-term impact of cognitive deficits	not validated in brain
	and epilepsy on quality of life in patients with low-grade	tumour populations
	meningiomas. Journal of Neurosurgery, 69(1), 72-78.	
30	Weitzner, M. A., Meyers, C. A., & Byrne, K. (1996).	The HRQofL
	Psychosocial functioning and quality of life in patients	measurement was
	with primary brain tumours. Journal of Neurosurgery,	not validated in brain
	84(1), 29-34.	tumour populations

Appendix C – Quality Assessment Tool

Adapted from the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011), STROBE (Vandenbroucke et al., 2007), Harden et al. (2004), Downs and Black (1998) and

Spencer, Ritchie, Lewis, and Dixon (2003).

-

				I	Responses		
Item		Criteria	Yes	Partly	No	Can't Tell	N/A
			2	1	0	0	
1		Abs	stract				•
		Does it provide an					
		informative and					
1		balanced summary of					
		what was done and the					
		major findings?					
2		Intro	duction				
		Was the scientific					
2i	Background	background and					
	and rationale	rationale for the					
		research explained?					
		Has it provided an					
		explanation or					
2ii	Key Concepts	definition of quality of					
	v i	life in the literature					
		review?1					
		Are the					
2iii		hypotheses/aims/					
		objectives of the study					
		clearly described?					
		Are the research					
2iv	Aims and	questions/aims/					
	Objectives	objectives amendable					
		to the chosen design?1					
		Is the primary study					
2v		aim to investigate					
		factors associated with					
		quality of life?1					
		Does it provide a					
2vi	Context	clinical rationale (i.e.					
		a real world issue that					
		justified the study)?					

3		Method and Res	ults (A	ll Designs	5)	
		Are the				
		characteristics of the				
		patients and how				
		they were recruited				
		clearly described?				
3i	Participant	Does it provide				
	Characteristics	adequate sample				
		details which are				
		critical to				
		understanding				
		findings (e.g. age,				
		gender, number of				
		tumour diagnosis)?				
		Is there adequate				
		description of the				
		measures used in				
		data collection (e σ				
311		description of				
511		questionnaire with				
	Methodology	reliability statistics				
	8)	and validation				
		information or				
		interview schedule)?				
		Is the procedure				
3iii		clear enough to be				
		replicable?1				
		Are all the statistical				
3iv	Data Analysis	tests/methods of				
		analysis used clearly				
		described?		.		
4		Method an	nd Resi	ults*		
		Are the sources of				
		qualitative data				
		documents				
Aai		informants				
ται		observations)				
	a. Qualitative	relevant to address				
	u Quintun (C	the research question				
		(objective)?				
		Is the process for				
		analysing qualitative				
4aii		data relevant to				
		address the research				
		question (objective)?				

4aiii		Has the detail, depth and complexity of data been conveyed well?			
4aiv		Are the links between data, interpretation and conclusions clear?			
4av		Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?			
4avi		Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?			
4bi		Are participants (organisations) recruited in a way that minimises selection bias?			
4bii		Are the reasons for non-participation and/or drop out stated?			
4biii	b. Quantitative non- randomised	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/ intervention and outcomes?			

4biv	Are the main findings relating to factors which influence quality of life clearly described? ²	o of
4bv	In the groups being compared (exposed vs. non-exposed; with intervention va without; cases vs. controls), are the participants comparable, or do researchers take int account (control for the difference between these groups?	g d vs. to pr)
4bvi	Are there complete outcome data (80% or above), and, whe applicable, an acceptable response rate (60% or above or an acceptable follow-up rate for cohort studies (depending on the duration of follow- up)?	e 6 ien se e), -
4bvii	Were the statistical tests used to assess the main outcomes appropriate?	1 s s
4bviii	Have actual probability values been reported (e.g., 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	., n s

5		Disc	ussion		
		Does it summarise			
5i	Key Results	key results with			
		reference to study			
		objectives?			
		Does it discuss			
		limitations of the			
		study, taking into			
		account sources of			
5ii	Limitations	potential bias or			
		imprecision? Does it			
		discuss both			
		direction and			
		magnitude of any			
		potential bias?			
		Does it give a			
		cautious overall			
		interpretation of			
····	T	results considering			
5111	Interpretation	objectives,			
		multiplicity of			
		analyza raculta			
		from similar studios			
		and other relevant			
		evidence?			
		Does it discuss the			
5iv	Generalisability	generalisability			
511	Generalisability	(external validity) of			
		the study results?			
5v	Implications	Does it discuss the			
51	Implications	implications and			
		clinical relevance of			
		the results? ¹			
L		· · · · · · ·			
		TOTAL SCORE			

Percentage Calculation

Study Design	Tick	Total Score		Percentage
Qualitative		/44	x 100	
Quantitative non-		/48		
randomised				

¹Item added ²Wording modified
Item	Criteria	Aaronson et al. (2011)	Brooker et al. (2009)	Budrukkar et al. (2009)	Hayhurst et al. (2011)	Jakola et al. (2012)	Kangas et al. (2012a)	Kangas et al (2012b)	Lamperti et al. (2012)	Ownsworth et al. (2010)	Porter et al. (2014)	Tsay et al. (2012)	van Nieuwenhuizen et al. (2007)	Yavas et al. (2012)	Total	Max Score
Abstract	Informative and balanced summary	1	2	2	2	2	2	2	2	2	2	2	2	2	25	26
	Background and															
	rationale	0	2	1	2	2	2	2	1	2	1	2	2	2	21	26
	Key Concepts	0	2	2	0	0	0	0	0	0	0	0	0	2	6	26
Introduction	Aims and Objectives															
	(Statement)	1	2	1	2	1	2	2	1	2	2	2	2	2	22	26
	Aims and Objectives															
	(Design)	2	2	1	2	0	2	2	1	1	2	2	1	1	19	26
	Aims and															
	Objectives	1	1	2	1	1	1	1	1	2	2	2	1	1	17	26
	(Primary Aim)		1	2	1	l	1	1	1	2	2	2	l	1	17	26
	Context	0	2	0	2	1	2	2	1	2	0	2	1	2	17	26

Appendix D – Methodological Quality Assessment

	Participant															
	Characteristics	2	2	2	1	2	2	2	1	2	2	1	2	1	22	26
Method and	Methodology															
Results (All	(Measures)	1	1	1	2	1	1	2	1	2	1	2	1	1	17	26
Designs)	Methodology															
	(Replicable)	1	2	2	2	1	1	1	0	1	2	0	1	0	14	26
	Data Analysis	2	2	2	2	1	2	2	2	2	2	2	2	1	24	26
*Qualitative	Sources		1		1										2	4
	Analyses		2		1										3	4
	Complexity		0		0										0	4
	Data/Conclusion															
	Links		1		0										1	4
	Context		0		0										0	4
	Researcher															
	Influence		1		0										1	4
*Quantitative	Recruitment	1		2		2	2	1	0	0	0	0	1	0	9	22
	Non-participation	1		1		1	1	0	1	2	2	1	1	1	12	22
	Measures	1		1		1	1	2	2	2	1	2	1	1	15	22
	Findings relating															
	to HRQofL	2		2		2	2	2	1	2	2	2	2	2	21	22
	Group															
	comparisons	2		0		1	1	2	0	1	1	2	0	0	10	22
	Complete data/															
	Response rate	2		2		2	1	2	1	2	1	0	0	1	14	22
	Appropriate															
	statistical tests	2		1		1	2	2	2	2	1	2	1	2	18	22
	Probability values	2		2		2	1	2	1	0	1	1	2	2	16	22

Discussion	Key Results	0	0	2	1	1	0	1	0	2	1	2	1	2	13	26
	Limitations	1	1	0	1	1	1	1	1	1	2	1	1	0	12	26
	Interpretation	0	1	1	1	1	1	2	1	1	1	1	1	1	13	26
	Generalisability	0	1	0	1	1	1	0	1	2	0	1	0	1	9	26
	Implications	0	1	0	0	2	2	2	1	2	1	2	0	1	14	26
Pei	rcentage	52%	66%	65%	55%	63%	69%	77%	48%	77%	63%	71%	54%	60%		

Appendix E – Data Extraction Tool

Study Characteristics

- Title of study
- Authors
- Year of publication
- Journal source
- Country of origin

Study Aims

- Study rationale
- Hypotheses

Participant Characteristics

- Sample size
- Age range
- Gender
- Ethnicity
- Population
- Type of brain tumour diagnosis/time since brain tumour diagnosis

Variables Studied and Measures

Study Design and Methodology

Statistical Analysis

Main Results

Conclusions and Implications

Main Limitations Identified

Quality Rating

Appendix G – Confirmation of Site Approval from Hull and East Yorkshire Hospitals NHS Trust

Appendix H – Confirmation of Site Approval from Leeds Teaching Hospitals NHS Trust

Appendix I – Patient Group Letter of Invitation

Richard Dearden Department of Clinical Psychology Hertford Building University of Hull Cottingham Road Hull HU6 7RX Telephone: (01482) 464106 (Secretary) Secure NHS Email: richard.dearden@nhs.net

Dear _____,

My name is Richard Dearden and I am a Trainee Clinical Psychologist studying at the University of Hull.

A member of your health care team, ______, has identified you as someone who would be interested in participating in a research project I am undertaking for my Doctorate titled *"Exploring patient-neurosurgical team relationships within the awake craniotomy context; a qualitative study"*. I would be most grateful if you could read the information sheet attached to this letter for more information about the study.

If having read this information sheet you are interested in taking part, could you please complete your contact details on the sheet provided and confirm with the relevant member of your healthcare team that these may be given to me. If you would prefer, you can contact me directly using the details at the bottom of the information sheet. I will then contact you to address any further questions you may have and if appropriate, arrange for us to meet.

Thank you for taking the time to read this letter.

Yours sincerely,

Richard Dearden (Trainee Clinical Psychologist)

Appendix J – Patient Group Information Sheet

Information Sheet for Patients

I am inviting you to take part in a research study. To help you decide if you wish to participate it is important that you understand why the research is being done and what is involved. Please take time to read the enclosed information carefully and discuss it with others should you wish. Ask if there is anything unclear to you or if you would like supplementary information. Please take all the time you need in deciding whether or not to take part. Thank you for taking the time to read this.

Exploring patient-neurosurgical team relationships within the awake craniotomy context; a qualitative study

What is the purpose of the study?

Previous research exploring patient views of awake craniotomy has the shown the importance of a good relationship with their care team. In particular, good communication is essential to this relationship. In this study both patients who have had an awake craniotomy and members of their neurosurgical team will be interviewed. The study aims to explore patient-neurosurgical team inter-relationships before, during and after the awake craniotomy with particular emphasis on aspects of communication. It is hoped that this research will help improve communication between patients having an awake craniotomy and members of their health care team.

Why have I been invited?

You have been selected as a potential candidate for this study because you have had an awake craniotomy.

Do I have to take part?

It is entirely for you to decide whether or not to take part. If you decide to take part please speak to the member of the health care team who approached you and keep this information sheet. The member of the health care team will give me your contact details and I will arrange to meet with you at a convenient time and place. When we meet I will give you an opportunity to ask any further questions and invite you to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or not to take part will have no affect on the standard of care you receive.

What will happen if I decide to take part?

If you agree to take part then you will be contacted by the researcher to arrange a meeting at a convenient time and place. You will have to answer some short questions about yourself, for example, your gender and your age. Then you will have a conversation with the researcher which will last around 60 minutes. The researcher, who is a trainee clinical psychologist, will be asking you some more questions about your experience of awake craniotomy and will audiotape the discussion. There are no right or

wrong answers and we are only interested in your options, your beliefs and your experiences.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about awake craniotomy. It may also help to improve relevant treatment plans and services.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be handled according to ethical and legal practice and kept secure and strictly confidential. You cannot be recognised from any of the information that you give me during our talk. After the results have been written up, all interview material will be destroyed.

What will happen to the results of the study?

The results will be written-up and submitted for publication in an academic journal. Some direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up. You can request a copy of the final paper from the researcher.

Who is organising and funding the research?

The research is being undertaken as part of a Doctoral research project in Clinical Psychology. The research is funded through the University of Hull.

Who has reviewed the study?

This study has been reviewed by the London – Hampstead Ethics Committee. They are a group of professional individuals who make sure that this study is proper and does not harm the people involved.

If you have any further questions, comments or queries, please don't hesitate to contact Richard Dearden. Thank you for taking the time to read this information.

Yours Sincerely,

Supervised by,

Richard Dearden Trainee Clinical Psychologist Dr Emma Wolverson Clinical Psychologist

Contact for Further Information

Richard Dearden, Trainee Clinical Psychologist Department of Clinical Psychology, University of Hull, Cottingham Road, Hull, HU6 7RX Telephone: (01482) 464106 (Secretary) Secure NHS Email: <u>richard.dearden@nhs.net</u> If you are interested to take part please leave your contact details in the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient time and place.

Name:	
Address.	
Telephone Number:	
Mobile Phone Number:	
Are there any times of the day that you prefer to be contacted?	
Do you have any further comments?	
	•••••
Signature:	
Date:	

Thank you very much

Appendix K – Patient Group Demographic Questionnaire

Participant Identification Number for the study:

Patient Group – Demographic Questionnaire

Gender (tick box as appropriate): Male Female								
Age:								
Grade of Tumour (tick box as appropriate): 1 2 3 4								
How long ago did you have the Awake Craniotomy?:								
Where in the brain was your tumour? (This does not have to be an exact location but just as you understand it $- e.g.$ front):								
Have you experienced any cognitive difficulties following the Awake Craniotomy? (e.g. memory, planning, problem solving, attention, understanding spoken material, understanding things you see etc):								
What level of support did your family give you before, during and while recovering from the Awake Craniotomy? (Please include the number of relatives who you felt supported by):								

 Appendix L – The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Appendix M – Patient Group Semi-Structured Interview Schedule

Interview Schedule – Patient Group

I would like to ask you some questions about your experiences with your neurosurgical team before, during and after having an Awake Craniotomy. Very little is known about this subject and I would like you to share your recollections whether they are positive or negative. This interview is entirely voluntary and if at any time you do not want to answer a particular question or want to stop, please let me know.

<u>Firstly, I would be interested to hear about the time before your Awake</u> <u>Craniotomy.</u>

- 1. How would you explain to someone what an Awake Craniotomy is?
- Can you tell me about your decision to have an Awake Craniotomy?
 a. (What factors influenced your decision?)
- 3. Can you tell me about your experiences with the neurosurgical team before the Awake Craniotomy?
 - a. (What was communicated to you?)
 - b. (How was it communicated to you?)
- 4. Can you tell me about your feelings before the operation?a. (Did you share any of these feelings with the neurosurgical team?)

<u>Can we move on now to talk about your experiences of the Awake</u> <u>Craniotomy procedure?</u>

- 5. Can you tell me about your experiences in the operating theatre?
- 6. Can you describe your experiences of the neurosurgical team in the operating theatre?
 - a. (What was communicated to you?)
 - b. (How was it communicated to you?)
- 7. I would be interested to hear about anything you found particularly difficult during the Awake Craniotomy procedure.
- 8. Can you tell me about anything you found particularly helpful during the Awake Craniotomy procedure?

<u>Can we move on now to talk about your experiences after the Awake</u> <u>Craniotomy procedure?</u>

9. I would be interested to hear about your experiences of recovering following the Awake Craniotomy procedure.

- 10. How would you describe your experiences of the neurosurgical team after the Awake Craniotomy procedure? (*participants could mention hospital care staff here)
 - a. (What was communicated to you?)
 - b. (How was it communicated to you?)
- 11. Can you tell me about your feelings after the Awake Craniotomy procedure?a. (Did you share any of these feelings with the neurosurgical team?)
- 12. Overall, looking back on this experience, how do you feel about the operation you had?

Is there anything else that you would like to share about your experiences of having an Awake Craniotomy?

Appendix N – Neurosurgical Team Member Group Letter of Invitation

Richard Dearden Department of Clinical Psychology Hertford Building University of Hull Cottingham Road Hull HU6 7RX Telephone: (01482) 464106 (Secretary) Secure NHS Email: richard.dearden@nhs.net

Dear _____,

My name is Richard Dearden and I am a Trainee Clinical Psychologist studying at the University of Hull.

Your name has been given to me by ______ because you are a member of a health care team with experience of awake craniotomy. I am writing to you to ask if you would be willing to participate in a research project I am undertaking for my Doctorate titled *"Exploring patient-neurosurgical team relationships within the awake craniotomy context; a qualitative study"*. I would be most grateful if you could read the information sheet attached to this letter for more information about the study.

I will contact you again by telephone within the next few days to ask if you have any further questions and invite you to participate. If you are willing to take part, we can arrange a suitable time and place to meet.

Thank you for taking the time to read this letter.

Yours sincerely,

Richard Dearden (Trainee Clinical Psychologist)

Appendix O – Neurosurgical Team Member Group Information Sheet

Information Sheet for Members of the Neurosurgical Team

I am inviting you to take part in a research study. To help you decide if you wish to participate it is important that you understand why the research is being conducted and what is involved. Please take time to read the enclosed information carefully and discuss it with others should you wish. Ask if there is anything unclear to you or if you would like supplementary information. Please take all the time you need in deciding whether or not to take part. Thank you for taking the time to read this.

Exploring patient-neurosurgical team relationships within the awake craniotomy context; a qualitative study

What is the purpose of the study?

Previous research exploring patient views of awake craniotomy has the shown the importance of a good relationship with their care team. In particular, good communication is essential to this relationship. In this study both patients who have had an awake craniotomy and members of their neurosurgical team will be interviewed. The study aims to explore patient-neurosurgical team inter-relationships before, during and after the awake craniotomy with particular emphasis on aspects of communication. It is hoped that this research will help improve communication between patients having an awake craniotomy and members of their health care team.

Why have I been invited?

You have been selected as a potential candidate for this study because you are a member of a neurosurgical team with experience of awake craniotomy.

Do I have to take part?

It is entirely for you to decide whether or not to take part. You will have received a written invitation to participate together with this information sheet which you may keep. I have been provided with your contact details and will be approaching you with an invitation to participate. If you decide to take part, I will arrange to meet with you at a convenient time and place. When we meet I will give you an opportunity to ask any further questions and invite you to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen if I decide to take part?

If you agree to take part then you will be contacted by the researcher to arrange a meeting at a convenient time and place. You will have to answer some short questions about yourself, for example, your gender and your age. Then you will have a conversation with the researcher which will last around 60 minutes. The researcher, who is a trainee clinical psychologist, will be asking you some more questions about your experience of awake craniotomy and will audiotape the discussion. There are no right or wrong answers and we are only interested in your options, your beliefs and your experiences.

What are the possible disadvantages and risks of taking part?

Participating in the study will require 60 minutes of your time and this may be inconvenient for you.

What are the possible benefits of taking part?

We cannot promise that you will have any direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about awake craniotomy. It may also help to improve relevant treatment plans and services.

What will happen if I decide I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and the study is written-up without giving a reason.

What if there is a problem?

If you have a concern about the study you can contact the researcher or their supervisor who will do their best to answer your questions.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be handled according to ethical and legal practice and kept secure and strictly confidential. You cannot be recognised from any of the information that you give me during our talk. After the results have been written-up, all interview material will be destroyed.

What will happen to the results of the study?

The results will be written-up and submitted for publication in an academic journal. Some direct quotes from your interview may be used in the write-up. Your personal details and any identifiable data **will not** be included in the write-up. You can request a copy of the final paper from the researcher.

Who is organising and funding the research?

The research is being undertaken as part of a Doctoral research project in Clinical Psychology. The research is funded through the University of Hull.

Who has reviewed the study?

This study has been reviewed by the London – Hampstead Ethics Committee. They are a group of professional individuals who make sure that this study is proper and does not harm the people involved.

If you have any further questions, comments or queries, please don't hesitate to contact Richard Dearden. Thank you for taking the time to read this information.

Yours Sincerely,

Supervised by,

Richard Dearden Trainee Clinical Psychologist Dr Emma Wolverson Clinical Psychologist

Contact for Further Information

Richard Dearden, Trainee Clinical Psychologist Department of Clinical Psychology, University of Hull, Cottingham Road, Hull, HU6 7RX Telephone: (01482) 464106 (Secretary) Secure NHS Email: <u>richard.dearden@nhs.net</u> If you are interested to take part please leave your contact details in the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient time and place.

Name:
Address:
Telephone Number:
Mobile Phone Number:
Are there any times of the day that you prefer to be contacted?
Do you have any further comments?

Signature:	
Date:	

Thank you very much

Appendix P – Neurosurgical Team Member Group Demographic Questionnaire

Participant Identification Number for the study:

<u>Neurosurgical Team Group – Demographic Questionnaire</u>

Gender (tick box	as appropriate):	Male	Female
Age:			
Job Title:			
Number of years	since qualification:		
How many years Craniotomy proc	have you been active edure?:	ely involved with the A	Awake
Have you had any appropriate)?:	y formal communicat	tion training (tick box	as
Yes	No		
(If you have answ	vered 'Yes', please w	vrite details below)	

Appendix Q – Neurosurgical Team Member Group Semi-Structured Interview Schedule

Interview Schedule – Members of the Neurosurgical Team

I would like to ask you some questions about your experiences and your understanding of patient experiences of Awake Craniotomy. Very little is known about this subject and I would like you to share your experiences whether they are positive or negative. This interview is entirely voluntary and if at any time you do not want to answer a particular question or want to stop, please let me know.

Firstly, I would be interested to hear about the time before a patient undergoes an Awake Craniotomy.

- 1. In your experiences, how do you think patients understand what an Awake Craniotomy is before their operation?
- 2. Can you tell me about how you explain to patients what an Awake Craniotomy is? (*for Neurosurgeons only)
- 3. Can you tell me about your understanding of how patients decide to have an Awake Craniotomy?
 - a. (What is your role in helping patients to make a decision?)
 - b. (How do patients feel at this time?)
- 4. Can you tell me about the role of the neurosurgical team before the Awake Craniotomy?
 - a. (What is communicated to patients?)
 - b. (How is it communicated to patients?)

Now I would like to move on to talk about your role, experiences and understanding of patient experiences during the Awake Craniotomy procedure itself.

First, in terms of your experience:

- 5. How do you feel when you are in the operating theatre during an Awake Craniotomy procedure?
- 6. Can you tell me about any things you find particularly helpful and unhelpful during the operating theatre process?

Secondly, in terms of patients' experiences:

- 7. Can you tell me about how you think patients experience the operating theatre during their Awake Craniotomy?
- 8. I would be interested to hear about your understanding of anything patients may find particularly helpful and unhelpful during surgery?

<u>Now I would like to hear about your role, experiences and understanding of patient experiences after the Awake Craniotomy procedure?</u>

- 9. Can you tell me about your experiences of patient recovery?
- 10. Can you tell me about the role of the neurosurgical team after a patient has undergone an Awake Craniotomy?
- 11. Can you tell me about your understanding of what constitutes a good outcome following the Awake Craniotomy procedure?
 - a. (I would be interested to hear about your understanding of what patients view as a good outcome?)
- 12. How do you think patients feel when looking back on their experiences of their Awake Craniotomy?

Is there anything else that you would like to share about your experiences or your understanding of patient experiences of Awake Craniotomy?

Signature

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Appendix R – Participant Consent Form

Participant identification number for the study:

CONSENT FORM

Title of Project: Exploring patient-neurosurgical team relationships within the awake craniotomy context; a qualitative study.

Name of Researcher: Richard Dearden

- 1. I confirm that I have read and understood the information sheet dated 15/05/2013 (Version 1.1) for the above study. I have had the opportunity to consider the information. Any questions I had have been answered satisfactorily by the researcher.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and without my medical care or legal rights being affected.
- 3. I confirm I am aware that the interview portion of this study will be digitally recorded using a Dictaphone.
- 4. I understand that this recording will be transcribed using a computer and made anonymous. Thereafter, the audio recording will be destroyed.
- 5. I agree to take part in the interview portion of the study and understand that this will be audio taped.

Name of person taking	Date	Signature
consent		

Date

Name of Participant

Please initial boxes



	-	

Appendix S – Epistemology Statement

Epistemology Statement

The way research is conducted can be influenced by our experiences of the world (Carter & Little, 2007). Although no 'correct' position exists when undertaking research, it is important to reflect on how different attitudes inform various approaches that yield diverse types of knowledge. Accordingly, consideration is warranted surrounding the epistemological and ontological assumptions that underpinned the researcher's choice of methodology and design to address study questions.

Epistemology is a 'theory of knowledge' and defines how reality is discovered (Doucet, Letourneau, & Stoppard, 2010), thereby influencing the relationship between participants and researcher (Ponterotto, 2005). Ontology relates to the nature of reality (Doucet et al., 2010) and attempts to ascertain what entities are real within the world and whether they can be known (Colman, 2006).

In choosing a research method and design for the empirical paper, the nature of study questions and topic area were considered. During initial research stages, it was identified that limited literature existed exploring either patient or neurosurgical team experiences of AC or perioperative interactions. There also seemed paucity of preexisting theory or hypotheses to test and concerns arose regarding whether quantitative measures could adequately capture the individualistic nature of AC experiences described in the qualitative report of Palese, Skrap, Fachin, Visioli, and Zannini (2008). Accordingly, research objectives were developed from a position of curiosity and exploration, where interest was placed on understanding subjective perceptions. Therefore, a positivist stance, predominantly associated with quantitative research, was rejected (Willig, 2001).

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The philosophy of positivism advocates scientific methods of research that involve systematic examination of phenomenon within the confines of theory, controlled experiments to test hypotheses and interpretation of statistical data (Ponterotto, 2005). It suggests one true form of reality exists that can be identified and measured to achieve objective knowledge (Willig, 2001). Positivism also emphasises dualism and objectivism where reality is determined by the participant being studied, with minimal influence or bias from the researcher (Onwuegbuzie, 2000). In contrast, constructionism rejects the concept of a 'true reality' and suggests reality is an idiosyncratic concept that is socially constructed and influenced through culture, relationships and use of language (Burr, 1995). This approach adheres to a relativist position and proposes many forms of reality can exist; valuing diversity in individual experience (Ponterotto, 2005; Morrow, 2007).

Qualitative research is informed predominantly by constructivist principles and aims to produce data based on the participants' own categories of meaning (Johnson & Onwuegbuzie, 2004). It is concerned primarily with how individuals subjectively make sense of phenomenon (Ashworth, 2008). Within clinical and health psychology literature, qualitative approaches are increasingly valued (Smith, 2008) and recognise how illness and treatment experiences are constructed, shaped and reflected upon as a person interacts with their world (Murray & Chamberlain, 1999). Accordingly, the researcher considered qualitative methodology as most suitable when aiming to explore both patients and neurosurgical team subjective experiences of AC and perioperative inter-relationships, especially given idiosyncratic perceptions are likely influenced by social and healthcare contexts.

Four qualitative approaches were considered: thematic analysis, discourse analysis, grounded theory and interpretative phenomenological analysis (IPA). Following detailed examination, IPA was viewed as most appropriate to address the research questions. The methodologies explored are discussed below:

Thematic Analysis

Thematic analysis is informed by an objectivist stance and is concerned with categorisation and description of common features across qualitative data rather than capturing individuals' experience (Anderson, 2007). Given interpretation has a minimal role in data analysis, which may limit comprehensive examination of phenomena, this methodology was rejected as the study aimed to understand rather than describe patient and neurosurgical team experiences of AC and their perioperative interactions.

Discourse Analysis

Discourse analysis focuses on the use of language within sociocultural contexts to describe experiences (Willig, 2001). However, this approach seems to ignore that communicating experience may involve more than words. Patients and members of the neurosurgical team may indicate perceptions of AC through non-verbal communication or parallel processes during relational interactions. Accordingly, discourse analysis was rejected as the study aimed to explore lived experiences of both parties and reach a deeper level of interpretation beyond usage of language.

Grounded Theory

The main objective of grounded theory is to develop new theory or refine existing theory which is cemented within analysed data (Strauss & Corbin, 1994).

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Theory is generated based on extensive interviewing that examines an experience sequentially, where themes generated from initial data sources are compared against later acquired data (Willig, 2001). Consistent with a positivist approach, grounded theory uses systematic techniques to study the world. However, it also assumes an interpretative stance, emphasising how people construct meaning (Smith, 2008). Despite inclusion of interpretative principles, the researcher did not intend to generate theory but aimed to explore subjective experiences. Furthermore, due to paucity of research examining AC experiences, limited opportunities existed to examine any existing theoretical frameworks. Accordingly, grounded theory was deemed inappropriate.

IPA

The chosen method of data analysis was IPA as it examines how individuals make sense of their experiences without attempting to create theory or draw conclusions (Smith, Flowers, & Larkin, 2009). Interestingly, IPA is used increasingly within health psychology, providing a useful approach for exploring how people understand and interpret their illness and treatment experiences, going beyond historical reductionist biomedical approaches (Brocki & Wearden, 2006). Theoretical assumptions underlying IPA include phenomenology, hermeneutics and idiography (Birkbeck, 2011).

Phenomenology refers to the study of people's experiences and ways of viewing the world (Barker, Pistrang, & Elliott 2002). Hermeneutics refer to theory and processes of interpretation which is a key principle of IPA (Birkbeck, 2011). Within this approach, a double-hermeneutic is evident, whereby participants are trying to make sense of their world and the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2008). Accordingly, the researcher's own conceptions are an integral part of the interpretative process when attempting to understand how both patients and neurosurgical team members make sense of their AC experiences. Finally, idiography refers to interest in the particular (Birkbeck, 2011), emphasising the idiosyncratic and complex nature of individual experiences and how indepth understanding of phenomenon beyond mere description is paramount (Ponterotto, 2005).

IPA was considered the most appropriate qualitative methodology to address study aims because its theoretical underpinnings placed emphasis on understanding individual experience. Although IPA recognises that it is difficult for the researcher to access complete idiosyncratic experiences of the individual, providing only partial insight into a person's world (Smith et al., 2009), there appeared potential to attend towards subjective perceptions instead of making generalisations. This seemed particularly important as both patients and neurosurgical team members AC experiences are reported to be highly individualistic and likely influenced by social and healthcare contexts (Palese et al., 2008). Therefore, study methodology and design are consistent with the concept of relativism, reflecting the researcher's epistemological and ontological position that reality is socially constructed.

References for Epistemology Statement

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Appendix T – Worked Example of Interpretative Phenomenological Analysis (IPA): Patient Group

A section of transcript from one patient follows to illustrate stages of the IPA process in the creation of themes. This excerpt is from an interview with 'John'.

Stage 1 Analysis

Transcripts were continually read and re-read to facilitate engagement and understanding of the whole text. Audio recording of the interview was also listened to during reading.

Stage 2 Analysis

The right hand margin of the transcript was used to note initial ideas, specific points, and to identify semantic content using descriptive, linguistic and conceptual comments, thereby facilitating reflexive engagement with the data.

Transcript	Initial Comments
Researcher: Can you tell me about your experiences in	
the operating theatre?	
John: I kept laughing because they kept asking me, you	Laughing – minimise the
know, what music do you want on, and I was just like I'm	seriousness of the situation
just about to have my brain cut open (*laughs), I really	Anxiety, assault on the brain, unnatural. ("cut open")
don't care about music ha ha (*laughs), and I'm not a	Request for music choice contrasts seriousness of brain
music person anyway, but, and then it was funny because	surgery – laughs in unbelief? Appropriate communication?

the physio said sort of, 'oh well, you want to be careful because, you know, they might put on something, you know, that one of the people likes that you might not like.' Trust me, I'm not going to be listening to music, uhm, so there is a general sense of, in the operating theatre of trying to relax you. Obviously, the anaesthetist then kind of starts to knock you out a little bit with local anaesthetic so they can clamp your head and things like that, and there's a lot of talking around you, clearly there's a huge amount of machinery and kit and whatever, and as John Cleese used to say, you know, the machine that goes bleep or whatever so, as long as it keeps going bleep you're alright but, so...And you also are there with your physio, you know, because you've done the functional MRI and so you have a relationship there and, to this day, that person, you know, will live in my memory forever, through whatever I go through because, you know, they were there and, you just can't explain it, you know, everyone was there for you but, you know, clearly most people have a job to do and other people kind of were probably only there in case there are other issues and, uhm, but it was quite difficult for me because as we went through the operation, I was having regular localised seizures in my arm, uhm, now on a positive note, I could sense in my hand when they were coming on, so I could tell my physio I think one's going

Use of humour by team member. Lighten the mood? Distraction? (Strategy to reduce anxiety?)

Focused on impending surgery – anxiety

Team tries to relax you, but still anxious

'Knocked out' (violent assault on body or not fully present/aware?)

'Clamped' – vulnerable/powerless

Unusual environment – unfamiliar visual stimuli, strange noises, voices; what's happening? Trying to process/make sense of it.

Machinery causes focus on mortality/operation – anxiety?

"with your physio" – doing it together, value of familiar relationship (emotional containment?)

Highly valued relationship Everlasting, remembered forever (essential for getting through it?) Constant presence Unexplainable intense feelings of gratitude

Team gets on with their duties/responsibilities (feel separate/isolated from them? Don't want to distract them?)

Experience of seizures – uncontrollable, terror, what's going on? Compromised ability to communicate with team?

Communicate with physio (being part of the team?

to happen and then it would happen, she had already told	Involved? Relationship facilitates this?)
the neurosurgeon, uhm, that I thought one was going to	Physio then communicates to neurosurgeon (the patient's voice? Intermediary?)
happen, so they were using cold saline solution on	Vivid awareness of operative
whatever part, onto my brain to try and stop the, and then	events (anxiety?)
if it did happen, they would wait and, and after about 5 or	
6 seizures, they kind of said 'look, do you think we	
should stop this?' And I thought that was a question they	Who are the team talking to? Am I separate from or
were having between themselves, and they were actually	(uncertain role? Anxiety?)
kind of asking me (*laughs).	Laughs – indicates anxiety/bizarreness of uncertain role experience? Trying to make sense of it?

Stage 3 Analysis

The left hand margin of transcripts was used to note emerging themes by mapping interrelations and connections within the transcript.

Emerging Themes	Transcript	Initial Comments
	Researcher: Can you tell me	
	about your experiences in the	
	operating theatre?	
Humour/Coping	John: I kept laughing because	Laughing – minimise the
(strategy initiated by	they kept asking me, you	senousness of the situation
patient)	know, what music do you want	
	on, and I was just like I'm just	
Bizarre/Unnatural event	about to have my brain cut	Anxiety, assault on the brain, unnatural. (<i>"cut open"</i>)
Anxiety	open (*laughs), I really don't	

Trying to make sense of it	care about music ha ha	Request for music choice contrasts seriousness of brain surgery – laughs in unbelief?
	("laughs), and I in not a music	Appropriate communication?
	person anyway, but, and then it	
	was funny because the physio	
Humour/Coping (strategy also used by	said sort of, 'oh well, you want	
team)	to be careful because, you	Use of humour by team member. Lighten the mood? Distraction? (Strategy to reduce anxiety?)
	know, they might put on	
	something, you know, that one	
	of the people likes that you	
	might not like.' Trust me, I'm	Focused on impending
Anxiety	not going to be listening to	
	music, uhm, so there is a	
	general sense of, in the	Team tries to relax you, but still anxious
	operating theatre of trying to	
	relax you. Obviously, the	'Vnoskad out' (vislant accoult
Powerlessness	anaesthetist then kind of starts	on body or not fully present/aware?)
	to knock you out a little bit	
Vulnerability	with local anaesthetic so they	'Clamped' – vulnerable/powerless
	can clamp your head and	
Unnatural/unusual	things like that, and there's a	Unusual environment – unfamiliar visual stimuli
environment	lot of talking around you,	strange noises, voices; what's happening? Trying to
Make sense of sensory	clearly there's a huge amount	process/make sense of it.
happening?)	of machinery and kit and	
Trying to make sense of it	whatever, and as John Cleese	
-	used to say, you know, the	
	machine that goes bleep or	Machinery causes focus on mortality/operation – anxiety?

Focus on seriousness of	whatever so, as long as it keeps	
procedure Anxiety	going bleep you're alright but,	
	soAnd you also are there	
Collaborative	with your physio, you know,	<i>"with your physio"</i> – doing it
Emotional containment	because you've done the	together, value of familiar relationship (emotional
Fammarity	functional MRI and so you	containment?)
	have a relationship there and,	
Essential relationshin	to this day, that person, you	Highly valued relationship Everlasting, remembered forever (essential for getting
Essential relationship	know, will live in my memory	through it?)
Highly emotional and	forever, through whatever I go	Constant presence Unexplainable intense feelings of gratitude
close relationship	through because, you know,	reenings of grantude
	they were there and, you just	
	can't explain it, you know,	
	everyone was there for you	
	but, you know, clearly most	Team gets on with their
Separated/isolated from	people have a job to do and	duties/responsibilities (feel separate/isolated from them? Don't want to distract them?)
team	other people kind of were	
	probably only there in case	
	there are other issues and, uhm,	
	but it was quite difficult for me	
	because as we went through	
	the operation, I was having	Experience of seizures –
Vulnerable	regular localised seizures in	uncontrollable, terror, what's going on? Compromised ability to communicate with
	my arm, uhm, now on a	team?
	positive note, I could sense in	
	my hand when they were	

	coming on, so I could tell my	
Part of team/involved/	physio I think one's going to	Communicate with physio
requires relationship	happen and then it would	(being part of the team? Involved? Relationship facilitates this?)
Phyiso as intermediary	happen, she had already told	
between patient and	the neurosurgeon, uhm, that I	Physio then communicates to neurosurgeon (the patient's
team	thought one was going to	voice? Intermediary?)
	happen, so they were using	
	cold saline solution on	
Vivid recollection	whatever part, onto my brain to	Vivid awareness of operative procedure and timescale of
	try and stop the, and then if it	events (anxiety?)
	did happen, they would wait	
	and, and after about 5 or 6	
	seizures, they kind of said	
What's my role?	'look, do you think we should	Who are the team talking to?
Anxiety	stop this?' And I thought that	Am I separate from or involved with the procedure?
it	was a question they were	(Uncertain role? Anxiety?)
	having between themselves,	
Bizarre experience	and they were actually kind of	Laughs – indicates
it	asking me (*laughs).	uncertain role experience? Trying to make sense of it?
		-

Stage 4 Analysis

Quotations from transcripts were identified to support emerging themes. Thereafter, themes were validated through a peer-IPA research group, research supervision and contacting research participants to ensure accounts had been well represented.

Emerging Theme	Supporting Quotes	
Trying to make sense of it	"I'm just about to have my brain cut open (*laughs)"	
Making sense of the unusual/bizarre environment (What's happening?)	"There's a lot of talking around you, clearly there's a huge amount of machinery and kit and whatever, and as John Cleese used to say, you know, the machine that goes bleep"	
Psychological reactions	"It was quite difficult for me because as we went	
(anxiety/powerlessness/	through the operation, I was having regular localised	
vulnerability/vivid	seizures in my arm"	
recollections)		
	"The anaesthetist then kind of starts to knock you out a	
	little bit with local anaesthetic so they can clamp your	
	head and things like that"	
	"As long as it keeps going bleep you're alright"	
	"They were using cold saline solution on whatever part, onto my brain"	
Coping/Humour	"I kept laughing"	
	"It was funny because the physio said sort of, 'oh well,	
	you want to be careful because, you know, they might	

	put on something, you know, that one of the people likes	
	that you might not like.""	
Intense emotional	"You have a relationship there and, to this day, that	
relationship (containment,	person, you know, will live in my memory forever,	
essential, remembered)	through whatever I go through because, you know, they	
	were there and, you just can't explain it"	
What's my role?	"They kind of said 'look, do you think we should stop	
(Uncertainty/Bizarre	this?' And I thought that was a question they were	
experience)	having between themselves, and they were actually kind	
	of asking me (*laughs)."	
Separate from the team	"Most people have a job to do"	
Part of the team	"I could sense in my hand when they were coming on,	
	so I could tell my physio"	
Physio as intermediary	"I could tell my physio I think one's going to happen	
	and then it would happen, she had already told the	
	neurosurgeon, uhm, that I thought one was going to	
	happen"	

Stage 5 Analysis

Following analysis of individual transcripts, emerging themes across cases were collated, facilitating development of superordinate and subordinate themes. These

themes were examined alongside transcripts to ensure they were grounded in the data.

Themes were not selected due to prevalence but in relation to richness of accounts.

Appendix U – Worked Example of Interpretative Phenomenological Analysis (IPA): Neurosurgical Team Member Group

A section of transcript from one patient follows to illustrate stages of the IPA process in the creation of themes. This excerpt is from an interview with 'Chris'.

Stage 1 Analysis

Transcripts were continually read and re-read to facilitate engagement and understanding of the whole text. Audio recording from the interview was also listened to during reading.

Stage 2 Analysis

The right hand margin of the transcript was used to note initial ideas, specific points and to identify semantic content using descriptive, linguistic and conceptual comments to inform reflexive engagement with the data.

Transcript	Initial Comments
Researcher: How do you feel when you're in the	
operating theatre doing an awake craniotomy?	
Chris: Um, if everything's been set-up and the, and the	Appropriate set-up
anaesthetist is someone I've worked with regularly then	(preparation?)
I'm usually pretty calm about the whole thing. We go on	Familiar team member (knows operative routine/experienced?) Teamwork?
and do it. From my point of view, I'm doing something I	Control facilitates calmness?
do every day, you know, regularly. I do a lot of tumour	Nothing difficult about conducting AC

operating so for me it's not a big deal. It is slightly more stressful because not only am I doing you know, although the operation I find fine, you know, I've also got to deal with the patient there and I'm, rather than just focusing in on taking a tumour out, I've got think about more things. I've got to think about functional aspects. I've got to think about where I'm stimulating. I've got to think about integrating what I'm doing with what the speech therapist is telling me and what the patient is telling me. And so there is more going on at any one time and as a surgeon it's easier for me to focus it on one thing than a bunch of you know, focus on what's going down on the motor strip rather than a bunch of things. So it is a bit more stressful. And you know sometimes you have to reassure the patient and chat to them and things like that rather than just getting on with what I'm doing. But ah, so yeah, but it's not that stressful.

Researcher: Can you tell me about the things that you find particularly helpful and unhelpful during the operating theatre process?

Chris: So helpful is getting the right position, getting the patient comfortable and for having made sure that we've all discussed what's happening beforehand so there's no surprises, there's nothing suddenly happens that you Stressful operation (contradiction?)

'Deal with' awake patient (inconvenience?)

Awake patient compromises focus and control?

Additional elements to consider (contributes to stress? Unable to simply get on with operation?)

Information from multiple sources (teamwork and patient, contributes to stress?)

Desire to remain focused but difficult due to many elements (always trying to maintain control?)

Managing numerous elements causes stress (reluctance to admit stress/struggle?)

Awake patient as an inconvenience? Difficult to focus?

'Not that stressful?' (contradiction? Reluctance to admit stress?)

Patient comfort (minimise unpredictability?)

Team is well informed about operative procedure

weren't expecting, that I know the people in theatre, that Accounting for all possible (everything is controlled		
there's not people chatting in the corner, all that sort of	Familiar team (experienced with protocol?)	
stuff and that we have decent image guidance and that	Appropriate behaviour in theatre (no chatting?)	
works, and the ultra sound and the microscope and all		
the normal sort of kit is working. That's all helpful.	Functioning equipment (everything is prepared/working/controlled?)	
What's unhelpful if I get many interruptions, if people	prepared, working/controlled.)	
come and talk to me about you know problems on the	Distractions are unhelpful	
wards or other issues and if (*pause) we had the film	Compromised control or focus? (contributes to stress?)	
crew in there does add to the stress level in the theatre	Film crew (distraction? Alter	
when they're filming. And, and we recently had one	way of working? More people in theatre?)	
patient that was, she was really odd during the		
procedure. She was a slightly odd personality anyway	'Odd' patient – inconvenience? Made it difficult to stay	
but she was just very strange. Um, and that, she wasn't	focused?	
the greatest choice shall we say for an awake but she got	Patient suitability (the right	
through it and she did very well in the end so um, I	choice for AC?)	
suppose I'm somewhat obsessing about these things and	'Obsessing' (need to preserve	
I like to know that's everything controlled when I'm	control at all times; causes stress?) How do you do this with an available patient	
doing it.	with an awake patient	
	Everything needs to be controlled	

Stage 3 Analysis

The left hand margin of transcripts was used to note emerging themes by mapping interrelations and connections within the transcript.

Emerging Themes	Transcript	Initial Comments
	Researcher: How do you feel	
	when you're in the operating	

	.1 . 1	
	theatre doing an awake	
	craniotomy?	
		Appropriate set-up (preparation?)
Controlled operating environment	Chris: Um, if everything's	Familiar team member (knows operative routine/experienced?)
Informed team/teamwork	been set-up and the, and the	Teamwork?
	anaesthetist is someone I've	Control facilitates calmness?
	worked with regularly then	
	I'm usually pretty calm about	
	the whole thing. We go on	
	and do it. From my point of	
	view, I'm doing something I	
Nothing difficult vs	do every day, you know,	Nothing difficult about
Being Stressed	regularly. I do a lot of tumour	conducting AC
	operating so for me it's not a	Stressful operation (contradiction?)
	big deal. It is slightly more	
Being out of control	stressful because not only am I	
(managing the awake	doing you know, although the	
patient)	operation I find fine, you	'Deal with' awake patient (inconvenience?)
	know, I've also got to deal	Awake patient compromises
Trying to maintain control and focus	with the patient there and I'm,	focus and control?
(coordination of numerous elements)	rather than just focusing in on	Additional elements to
numerous crements)	taking a tumour out, I've got	consider (contributes to stress? Unable to simply get on with
	think about more things. I've	operation?)
	got to think about functional	
	aspects. I've got to think about	
Team working	where I'm stimulating. I've	

	got to think about integrating	
Trying to maintain control and focus (coordination of numerous elements)	what I'm doing with what the	Information from multiple sources (teamwork and patient
	speech therapist is telling me	contributes to stress?)
	and what the patient is telling	
	me. And so there is more	
	going on at any one time and	Desire to remain focused but difficult due to many elements
	as a surgeon it's easier for me	(always trying to maintain control?)
	to focus it on one thing than a	
	bunch of you know, focus on	
Being stressed	what's going down on the	Managing numerous elements
	motor strip rather than a bunch	causes stress (reluctance to admit stress/struggle?)
	of things. So it is a bit more	
Managing the awake	stressful. And you know	
patient (distraction?)	sometimes you have to	Awake patient as an
	reassure the patient and chat to	focus?
	them and things like that	
Not stressful	rather than just getting on with	'Not that stressful?'
	what I'm doing. But ah, so	(contradiction? Reluctance to admit stress?)
	yeah, but it's not that stressful.	
	Researcher: Can you tell me	
	about the things that you find	
	particularly helpful and	
	unhelpful during the operating	
	theatre process?	

Minimise adverse	Chris: So helpful is getting the	
patient reactions	right position, getting the	Patient comfort (minimise
	patient comfortable and for	
Informed team	having made sure that we've	Team is well informed about
	all discussed what's happening	operative procedure
Preparation (control?)	beforehand so there's no	Accounting for all possibilities (everything is controlled?)
	surprises, there's nothing	
Appropriate Teamwork	suddenly happens that you	Familiar team (experienced with protocol?)
Appropriate Teamwork	weren't expecting, that I know	
	the people in theatre, that	
	there's not people chatting in	Appropriate behaviour in theatre (no chatting?)
	the corner, all that sort of stuff	
Preparation of	and that we have decent image	
equipment (control?)	guidance and that works, and	Functioning equipment (everything is
	the ultra sound and the	prepared/working/controlled?)
	microscope and all the normal	
	sort of kit is working. That's	
	all helpful. What's unhelpful if	
Minimise distractions	I get many interruptions, if	Distractions are unhelpful Compromised control or focus?
	people come and talk to me	(Contributes to stress?)
	about you know problems on	
	the wards or other issues and if	Film crew (distraction? Alter
	(*pause) we had the film crew	way of working? More people in theatre?)
	in there does add to the stress	
	level in the theatre when	
	they're filming. And, and we	

Managing the awake patient	recently had one patient that	'Odd' patient – inconvenience?
1	was, she was really odd during	Made it difficult to stay focused?
	the procedure. She was a	
	slightly odd personality	
	anyway but she was just very	
Patient Suitability	strange. Um, and that, she	
	wasn't the greatest choice	Patient suitability (the right choice for AC?)
	shall we say for an awake but	
	she got through it and she did	د
Intense focus on	very well in the end so um, I	
maintaining control	suppose I'm somewhat	Obsessing' (need to preserve
	obsessing about these things	control at all times; causes stress?) How do you do this with an awake patient
	and I like to know that's	
	everything controlled when	Everything needs to be controlled
	I'm doing it.	

Stage 4 Analysis

Quotations from transcripts were identified to support emerging themes. Thereafter, themes were validated through a peer-IPA research group, research supervision and contacting participants to ensure accounts had been well represented.

Emerging Theme	Supporting Quotes
Stress	"It is slightly more stressful"
Vs.	"So it is a bit more stressful"
Calmness	"I'm usually pretty calm about the whole thing"
	"I'm doing something I do every day"

Informed/Experienced	The anaesthetist is someone I've worked with
team (Appropriate	regularly"
Teamwork)	
	"Integrating what I'm doing with what the speech
	therapist is telling me"
	"We've all discussed what's happening beforehand so
	there's no surprises, there's nothing suddenly happens
	that you weren't expecting, that I know the people in
	theatre, that there's not people chatting in the corner"
Controlled operating	"We have decent image guidance and that works, and
environment (Preparation,	the ultra sound and the microscope and all the normal
minimisation of	sort of kit is working"
distractions and possible	
adverse patient reactions)	"What's unhelpful if I get many interruptions, if people
	come and talk to me about you know problems on the
	wards or other issues and if (*pause) we had the film
	crew in there does add to the stress level in the theatre
	when they're filming."
	"Getting the right position, getting the patient
	comfortable"

Trying to maintain control	"I've got think about more things. I've got to think about
and focus (coordination of	functional aspects. I've got to think about where I'm
numerous elements)	stimulating"
	"There is more going on at any one time and as a surgeon it's easier for me to focus it on one thing than a
	bunch of you know, focus on what's going down on the
	motor strip rather than a bunch of things."
Managing the awake	"We recently had one patient that was, she was really
patient (being out of	odd during the procedure."
control/unpredictable)	
	"Sometimes you have to reassure the patient and chat to
	them and things like that rather than just getting on with
	what I'm doing"
Patient Suitability	"She wasn't the greatest choice shall we say for an
	awake"

Stage 5 Analysis

Following analysis of individual transcripts, emerging themes across cases were collated, facilitating development of superordinate and subordinate themes. These themes were examined alongside transcripts to ensure they were grounded in the data. Themes were not selected due to prevalence but in relation to richness of accounts.

Appendix V – Reflective Statement

Reflective Statement

My research sojourn has provided a diversity of sometimes conflicting experiences. This statement attempts to outline core events throughout the process and provide my associated thoughts and emotions, concluding with final reflections on what I have assimilated and my aspirations for the future.

Developing the study

Selecting a subject for research

My previous positive experiences of researching aspects of neuropsychology led me to consider undertaking a piece of research in a relatively poorly investigated domain. In particular, I wanted my study to impact beyond merely obtaining a higher qualification. Accordingly, I considered a number of comparatively rare neurodegenerative conditions before developing a fascination for the concept of helping a patient through awake surgery for brain tumour. Subsequent discussions with members of my department highlighted the paucity of information surrounding experiences of either patients or their care team throughout the awake craniotomy process. Thereafter, I came to the conclusion that this could provide a fascinating and challenging domain for research, being advised that while ambitious, it would be highly desirable and unique to study both groups simultaneously.

Designing the study

One of the biggest challenges emerged after exploring available literature that recommended an exploratory qualitative approach given all my previous experience involved quantitative methodology. Further discussions with my supervisors' emphasised that an optimal approach should use interpretative phenomenological analysis (IPA). On reflection, I would have preferred a quantitative analytic process to remain in my comfort zone. Nevertheless, despite my apprehensions, it is clear that while extremely challenging and at times frustrating, my knowledge and tenacity has been substantially enhanced by selecting a qualitative design. Moreover, given my person-centred values as a psychologist, the concept and ideology of IPA was appealing because of its ability to allow individual perspectives and experiences to be ascertained.

Recruitment

To my surprise, recruitment of volunteers from both study groups was relatively easy, emphasising participants' enthusiasm to discuss their experiences. Despite my awareness that IPA is normally conducted with a non-prescriptive sample, on reflection, my previous conviction of an adequate sample size probably resulted in my recruiting far too many participants. Accordingly, I travelled to neurosurgical departments and patients homes all over the country and probably spent far too long acquiring an extremely detailed and robust dataset. This proved extremely challenging because of the logistics when trying to conduct research and avoid disruption in different departments which employed diverse methods of working. Moreover, it was frustrating when I had driven many miles to find clinicians were unable to make our arranged appointments. On reflection however, I believe this exercise helped me hone and refine my skills to

promote research through collaboration with other colleagues while maintaining their clinical duties.

Interviews

Fairly early in the interview process, I came to appreciate the contribution of IPA in enabling participants to 'tell their story'. Interviewing patients proved a real privilege, being inspired by their resilience and endurance, although sometimes I found the harrowing accounts of their treatment experiences extremely challenging. In contrast, I was initially apprehensive during interviews with clinicians, particularly neurosurgeons, and while this abated with experience, I was led to contemplate how patients must have felt in their 'expert' presence. One of the challenges of the interview process was segregating my role as researcher from that of psychologist, and while I sometimes felt constrained by being unable to intervene clinically, I believe that the interview experience probably provided some inherent therapeutic benefit.

Data analysis, writing the empirical paper and choosing a journal

Despite my anticipation that qualitative analysis would be lengthy, on reflection, I was totally unprepared for just how arduous and time consuming it would prove. Initially, I transcribed full interviews from 13 patients and 13 neurosurgical team members but this proved so time consuming that despite discussions with my supervisors, it was clear thesis deadlines could not be met. Since the dataset was saturated for both groups at eight participants I decided the only way to resolve the time constraints with the ethical responsibility of appropriate investigation was to select the first eight participants from each group, thereby minimising any selection bias. Despite this strategy, it also became apparent that I would need to extend my thesis deadline to do justice to the research.

One of the greatest challenges yet paradoxically most rewarding aspects of choosing a qualitative analytical approach was coming to terms with my realisation that previous quantitative research experiences had implanted the perception of a 'correct' or 'incorrect' approach. Accordingly, I was challenged to accept that there is no absolute 'right' way to use IPA since findings will always embody subjective elements from the researcher. I came to appreciate the influence of my emotive responses to both harrowing and humorous elements of participants' accounts, and my frustration at the inadequacy of a medical model approach advocated by the neurosurgical team. Moreover, I found myself empathising increasingly on the side of the patient, influenced through my training as a clinical psychologist, informed by a holistic biopsychosocial model. Accordingly, to maintain focus, challenge bias, and validate emerging themes, I sought support from a peer IPA research group and my supervisors while maintaining a reflective diary to acknowledge my emotions.

In particular, I felt challenged throughout both data collection and analysis to 'bracket' my own biases and assumptions to minimise compromising accurate representation of participants' lived experiences. My reflexivity was enabled through an honest examination of personal values and conflicts of interest that had potential to impinge upon the research process. I became aware during the initial interviews that my feelings were very different between the two participant groups. When speaking with patients, I enjoyed hearing their stories and felt at ease, but during my time with the quintessential 'expert' neurosurgical team members, I felt more anxious and intimidated, sometimes feeling frustrated by their apparent 'devotion' to a medical model. While imagining what a perceived power-imbalanced situation could have been like for 'vulnerable' patients, I found myself empathising with the patient group,

endangering my neutrality. I believe this represented my greatest source of bias, becoming most apparent to me while analysing intraoperative accounts. I found it very challenging to contrast patients' recall of highly distressing experiences with team members' reports surrounding the challenges imposed by 'awake' patients, especially an inability to maintain objectivity. My strong and delicate 'anti-team' views were highlighted during research supervision and discussions within a peer IPA group. In order to facilitate a more balanced and neutral approach, my supervisors and colleagues assisted me to consider alternative interpretations from the data, which facilitated a meta-cognitive position. Ongoing supervision helped me to remain aware of my own biases. I reflected on how becoming emotionally close to patients could compromise a neurosurgeon's ability to operate when the patient was awake. Specifically, I became able to acknowledge and appreciate that a degree of professional detachment was probably required. In order to maintain this meta-cognitive position, I kept a reflective diary to allow constant reframing of data interpretations.

Given that this research is the first to investigate both patients and neurosurgical team members simultaneously, the prospect of providing a comparative meta-synthesis was considered. However, after deliberations with acknowledged experts in this field, I was advised that it is unclear how to synthesise and report qualitative data from two similar groups at this time, although this might be possible in the future. Therefore, a narrative synergy of findings from both groups was attempted only in the discussion.

The plethora of rich and comprehensive experiences made selection of quotes to represent the themes selected for the empirical paper arduous. In particular, the wish to represent all the participants' voices had to be constrained against the desire for brevity. Accordingly, I sought advice from my supervisors to ensure that all participants' accounts could be represented by selecting only a few quotes and yet remain embedded within the foundations of each theme.

Another challenge was the selection of an appropriate journal to publish findings. I selected the *Journal of Brain Impairment* because it has published the majority of qualitative research in this area and accepts a 'no-word-limit' approach, acknowledging the verbosity and subjectivity of this literature.

Systematic Literature Review

My initial approach to reviewing relevant literature failed to acknowledge its pivotal importance when writing a thesis. The diversity of methodological approaches to a subject with very limited research was concerning and challenged my decision to investigate this area. Accordingly, I found compiling relevant data difficult, undoubtedly underestimated the amount of time needed and initially failed to appreciate the importance of the review process. However, on reflection, I have come to appreciate how valuable this exercise was because it enhanced my knowledge and widened my perspectives on how different researchers have approached the topic.

The journey so far...

There is no doubt that my first experiences of a qualitative approach to research has invoked mixed feelings. While writing this thesis has undeniably been a positive experience, greatly enhancing my analytical skills, it has also taken a huge amount of time and impacted my lifestyle. I very much hope to continue with clinical research and undoubtedly would wish to consider using IPA in the future as a compliment to quantitative research because uniquely it allows the individual's experience to be heard. However, I would also have to consider the impact of any analytic method on work-life balance when choosing the feasibility of future projects.

I have reflected on what I would do differently and concluded that the only major difference would have been to select a much smaller study sample, thereby making this exercise far less time consuming and yet avoiding compromising results.

My final thoughts are a mixed sense of relief and achievement at completing my first thesis. While I am apprehensive at the prospect of being outside an academic environment for the first time in my life, I am looking forward to the beginning of my career as a Clinical Psychologist.