AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF THE PATIENT EXPERIENCE OF AWAKE CRANIOTOMY: BRAIN TUMOUR DIAGNOSIS TO DISCHARGE

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Thesis Abstract

Introduction. This thesis explored patient experiences of awake craniotomy. Existing literature is scarce and dominated by quantitative methodologies. More recently two qualitative studies have provided a rich, but contrasting, understanding of the patients' experience of awake craniotomy. The methodological weaknesses of the existing literature are addressed, and the rationale for the study justified.

Objectives. The aim of the study was to explore seven participants' experiences of awake craniotomy using interpretative phenomenological analysis.

Methods. Single-site ethical approval was gained to conduct the study in one NHS Trust. All potential participants were approached who had undergone the awake craniotomy procedure at the NHS Trust.   Semi-structured interviews were conducted with participants. Interviews were transcribed verbatim and analysed using an interpretative phenomenological analysis framework.

Results. Analysis of transcripts yielded three superordinate themes: *self-preservation*, *operation environment* and *information.* The superordinate themes were interpreted as interconnected with each other, as well as embedded in a core theme: *relationship with the neurosurgeon.* The three superordinate themes are presented and discussed within the journal article. The extended paper elaborates on two of these superordinate themes.

Discussion. The *relationship with the neurosurgeon* appears crucial to the patients' experience of awake craniotomy. The relationship could impact on the participants' decision to have the awake craniotomy, their experience of the awake operation and their acceptance of the *information* given. The results are discussed with reference to previous literature. The implications and recommendations for further research are outlined.

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Contents

List of Tables

List of Figures

List of Appendices

Article for submission to the "Journal of Neurosurgery"

[See 1.0 in extended paper for rationale for journal choice and link to authors' instructions]

An Interpretative Phenomenological Analysis of the Patient Experience of Awake Craniotomy: Brain Tumour Diagnosis to Discharge

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Abstract

Object: Previous research exploring the patient experience of awake craniotomy has yielded inconsistent results. In the current study the authors aimed to explore the lived experience of having undergone an awake craniotomy in the United Kingdom.

Methods: Seven participants took part in the study, which used a qualitative research methodology. Each participant was interviewed using a semi-structured interview schedule. Interviews were audio recorded and transcribed verbatim. Transcripts were analysed using interpretative phenomenological analysis.

Results: Three superordinate themes: *self-preservation, operation environment* and *information* were identified. It was interpreted that each of these themes was embedded in a core theme: *relationship with the neurosurgeon.*

Conclusions: The *relationship with the neurosurgeon* appears crucial to the patient experience of awake craniotomy: from brain tumour diagnosis to discharge. This knowledge requires consideration in clinical settings and could lead to improved delivery of care in the future.

Key Words: * Awake craniotomy * Patient experience * Patient perception * Qualitative research * Interpretative phenomenological analysis * Lived experience

<u>Introduction</u>

An estimated 6500 people are diagnosed with a brain tumour in the United Kingdom (UK) each year[69]. Although rare, brain tumour prevalence is rising[27]. Treatment options for the safe removal of brain tumours have advanced in recent years. This is particularly relevant where the tumour is close to functionally eloquent areas of the brain, for example motor or language areas[10]. When removing such tumours an awake craniotomy procedure is thought to be a preferential[65], well established and safe technique[14,17]. *[See section 2.1 in extended paper for further discussion on the brain tumour and section 2.2 for further discussion on treatment options]*

The awake craniotomy aims to re-sect the maximum amount of brain tumour possible whilst the patient is awake and fully responsive[49,85]. Advantages of awake craniotomy, in contrast to traditional surgical procedure, include minimising the probability of damaging functionally eloquent cortex[14,17,49,65,85] as the surgical team can assess patient responses during the procedure. Preserving patient function is thought to improve quality of life[89]. In addition awake craniotomy could avoid complications caused by general anaesthesia and minimise utilisation of resources[5] through, for example, a reduction in length of hospital stay[76]. *[See section 2.3 in extended paper for further discussion on patient quality of life]*

Despite the reported advantages of awake craniotomy, it could be argued that little is truly understood about the patient experience[4], particularly in the UK. To date the majority of published studies on patient experience have reported satisfaction with[17,43,63], and tolerance of[71,63,74,85,90], awake craniotomy. However the majority of these findings have been fraught with methodological constraints, for example research failing to report how participant accounts were obtained[18,74,85]. Where the complexity of the methodology has improved[17,32,63,90], conclusions are potentially compromised by a lack of transparency[63,90] or biased through a member of the surgical team conducting the data collection[5]. For example, one study reported that all participants were entirely satisfied despite results suggesting that 25% of participants found the experience uncomfortable, anxiety provoking and fearful[74]. *[See 2.4 in extended*

paper for further discussion on patient experience of awake craniotomy literature]

To provide a more comprehensive account of this experience, two studies have utilised thematic analysis[43] and phenomenological analysis[71] to explore patient experience. The thematic study[43] reported positive reflections on the awake craniotomy experience. This was characterised by patient satisfaction, understanding of the rationale, surprise at the novel concept, a greater concern about the disease process and trust in one's surgeon. In contrast to previous research the phenomenological study[71] reported a tolerable but more anxiety provoking experience. Four key themes were identified: self-preservation, working out their role in the operation, having the situation under control and seeking reassurance for themselves and others. Although a positive step forward to exploring the awake craniotomy experience each study had methodological drawbacks. These included conducting interviews prior to and following awake surgery[43,71], potentially creating a superficial split in the reporting of the experience, and one study asked participants directed questions[43]. In addition, given that each study was conducted outside of the UK the potential for differences in the operation procedure are high. *[See 2.4 in extended paper for further discussion on qualitative studies]*

In light of the paucity of research in this area, the inconsistent findings and methodological constraints reported, further exploration of the patient experience of awake craniotomy, from brain tumour diagnosis to discharge is essential. This is particularly relevant when considering the diversification of awake craniotomy to remove tumours in any area of the brain[76,81] and to remove tumours in adolescents[64]. As patients' experiences of awake craniotomy may differ between countries, according to operation procedure, it is essential to explore, for the first time, the patient experience of awake craniotomy in the UK. Using interpretative phenomenological analysis, the aim of this study was to broaden the evidence base and facilitate understanding for neurosurgery teams and prospective patients about the lived experience of awake craniotomy.

<u>Methods</u>

Study Design

This was a retrospective qualitative study. The study utilised interpretative phenomenological analysis (IPA)[77] to explore patients' experiences of awake craniotomy. IPA is interested in the way people make sense of unique events[78]. In the current study IPA[77] was utilised to explore how people make sense of their awake craniotomy experience. To achieve this, the researcher attempted to make sense of the participant trying to make sense of their experience[78]. *[See 3.1 in extended paper for discussion on the study rationale]*

Participants

Eight participants' were recruited from a Department of Neurosurgery in the UK. 11 potential participants who had undergone awake craniotomy received an information pack (see appendix A, B & C). This was sent out from the Department of Neurosurgery on behalf of the research team. Participants were included if they had undergone an awake craniotomy procedure and if they were over 18 years of age. Participants were excluded if they did not speak English or if they had problems with speech. No selection criteria were set for the time since the procedure or other medical factors.

Seven of eight potential participants who contacted the lead author (KF) took part in the study. One interview was terminated and the data withdrawn from the analysis. This participant became distressed during the interview and, when asked, expressed that he would prefer to terminate the interview, leaving a sample size of seven. *[See 3.2 in extended paper for further discussion on participants and 3.3 for further discussion on participant recruitment]*

Data Collection

One semi-structured interview was conducted with each participant. All interviews were conducted by KF at the participants' home and were audio recorded. Interview duration, as planned, ranged between 46 and 70 minutes. Interviews were based on an interview schedule developed by the research

team (see Table 1). The schedule followed a temporal sequence to explore the experience of awake craniotomy in its entirety. Following IPA methodology, the interview schedule was not referred to directly during the interview. The lead author's knowledge of the schedule was sufficient to loosely follow the questions in line with interests and views offered by the participant thereby not directing the participants and permitting them to say what they felt was important to them, but at the same time maintaining a basic framework of inquiry. Prompts were employed throughout interviews to clarify questions or encourage responding. Demographic data (see appendix D), including gender, age and time since awake craniotomy, was also collected from participants to describe the sample (see Table 2). *[See 3.4 in extended paper for further discussion on data collection]*

Table 1

Interview Schedule

- Tell me about your decision to have an awake craniotomy
- Having made the decision how did you feel
    - o Before
        - ▪ How did you prepare yourself?
    - o On the day
    - o During
        - ▪ Can you tell me about your awake craniotomy?
    - o After
        - ▪ What did you think about the experience?
    - o At home
- How has life changed?
- What happened afterwards?

Data Analysis

Audio recordings of all interviews were transcribed verbatim. Transcripts were analysed in detail by KF. Data analysis followed an adapted version of the

stages of IPA[78].   Initially, transcripts were read and re-read, noting down descriptive, linguistic and conceptual comments in the right margin.   Second, emerging themes were noted in the left margin.   Third, themes were listed and superordinate and subordinate themes were identified.   On completion of a transcript the researcher commenced further transcripts on a case-by-case basis.   On completion of individual transcript analysis all themes were collated, organised and combined.   *[See 3.5 in extended paper for further discussion on the analysis process]*

During analysis the lead author did not attempt to withhold or 'bracket' previous knowledge and experience as this process is not supported by IPA.   Rather, keeping with the lead author's epistemological frame of critical realism, previous knowledge and experience informed interpretation *[see 3.1 in extended paper for further discussion on the epistemological position of the lead author]*

Quality Assurance

Quality assurance measures[91] were followed closely by the research team. Attempts were made to establish the *trustworthiness* of the findings[60]. *Trustworthiness* was sought through keeping an audit trail of analytical decision making, as well as a reflective diary.   The audit trail ensured *transparency* throughout the decision making process.   The journey to all themes identified can be traced through the analysis process from audio recording to write-up. This was made explicit through the provision of quotes in this article, ensuring the write-up has *credibility*.   Furthermore, the other authors (RdN and JM) also appraised the coding of the data in terms of the thematic structure and content, to examine whether they could 'see' what the lead researcher was seeing in the data.

The reflective diary was utilised from initial contact with participants to final write up.   This enabled the researcher to document considerations about previous knowledge and experience which may impact on data analysis or write up.   *[See 3.6 in extended paper for further discussion on quality assurance measures]*

Research Ethics

Participation was voluntary and informed consent was obtained. Data which could reveal participant identity was made anonymous using pseudonyms. Audio recordings and full, anonymous, transcripts were securely stored. The study was approved by the Leicestershire, Northamptonshire and Rutland NHS Research Ethics Committee 1 (Appendix E) and a NHS Trust research and development department (Appendix F). *[See 3.7 in extended paper for further discussion on ethical considerations and seeking ethical approval]*

<u>Results</u>

Seven participants (three males, four females) were recruited to the study between January and May 2010. Participants ranged from 26 to 41 years of age at the time of interview. Time since awake craniotomy ranged between five months and four years. Two neurosurgeons conducted the awake craniotomy procedures explored in this study. Where referred to directly, the neurosurgeons have been given pseudonyms. For sample characteristics see Table 2.

Table 2

Participant Information

Participant pseudonym	Age at interview	Time since craniotomy
Sundeep	28	5 months
Jen	35	32 months
Jo	26	48 months
Rachel	28	37 months
Emma	32	36 months
Craig	29	19 months
Ben	41	16 months

Analysis of transcripts produced three superordinate themes: *self-preservation*, *operation environment* and *information.* The superordinate themes were interpreted as interconnected with each other, as well as embedded in a core theme: *relationship with the neurosurgeon.* Figure 1 illustrates the relationship between the core theme and superordinate themes. *Relationship with the neurosurgeon* is central to the diagram as it was viewed as crucial to the experience of awake craniotomy. During analysis all participants' accounts were taken in to consideration. However for the purpose of this article quotes have been selected to facilitate the illustration of themes.
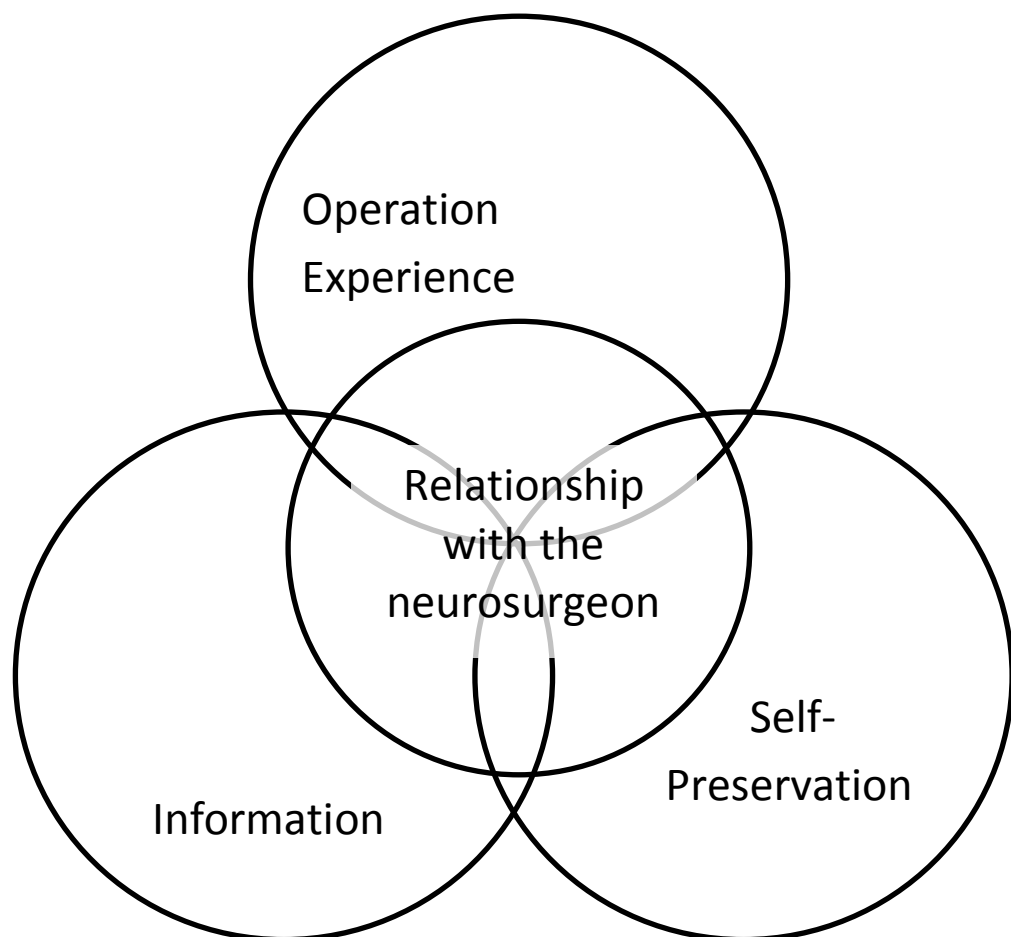

Figure 1: Schematic representation of the relationship between identified themes

Self-preservation

The theme *self-preservation* encompassed ideas presented by participants about their thoughts regarding the risks of the awake craniotomy procedure. Participants used a variety of strategies for *self-preservation* in this process. As with other themes the *relationship with the neurosurgeon* was embedded within it.

It was understood that participants were aware of the potential consequences of going ahead with the awake craniotomy procedure:

> Jen: ...you could be left paralysed and I think that was quite scary at first

> Sundeep: ...I'd sort of made my decision at that particular time [of going in for awake craniotomy], in that this could possibly be the last time [pause] I see anyone

Due to these frightening consequences participants described coping with the experience of preparing for the awake craniotomy by avoiding or distracting themselves from thinking about the operation:

> Jen: ...so I don't really think I actually thought about what they were going to do, I suppose, you know, black it out of your mind a little bit

> Emma: ...I just thought if I don't think about it then I can't worry about it

In the above extracts, Jen and Emma described making a conscious effort not to think about the upcoming awake craniotomy. Other participants actively focused their attention and thoughts on areas of their life other than the operation. For some this was seeking spiritual support and for others this was through humour:

> Sundeep: ...we [Sundeep and his family] spent a lot of time praying, in terms of the way I felt, it's I felt [long pause] almost [pause] as if I wasn't there, because these sorts of things were happening, but they were happening around me, as if they were happening to somebody else, umm detached I think is the word

> Rachel: ...it is scary but it's one of those things that if you didn't laugh about it you'd cry so you just have to get on with it

It was interpreted that coping through distraction, avoidance, external focus and humour were acting as *self-preservation* strategies for the participants. This was illustrated by Jo who described needing to do anything except sit and think about the awake craniotomy:

> Jo: ...I was quite frightened before [the awake craniotomy]...I went back to work and stuff and yeah I suppose that helped...it meant I was just getting on with like normal normal stuff...I'm glad I did that rather than sitting at home because I think I really would have wound myself up

The use of *self-preservation* strategies appeared to be reflected in all of the participants' decisions to have the awake craniotomy. Due to the emotional intensity of the decision and participant awareness of the implications of any decision made, they appeared to cope with the decision by placing responsibility on the neurosurgeon:

> Sundeep: ...I left everything in the hands of the [neuro]surgeon, what else can I do you know, that's the way my mind works...stop worrying about it, can't change it

> Craig: ...you put your life in the hands of the [neuro]surgeon and you just trust them

> Jen:...Once the consultant [neurosurgeon] recommended it, said this is how I want to do it, umm I just deci-, well I just thought well he's the expert, he knows what he's talking about, so I'll just, I'll just agree with, with what he wants to do really

In order to place this extreme amount of trust on the neurosurgeon it was interpreted that participants must have taken in to account their *relationship with the neurosurgeon*. This appeared to be over and above the status of the neurosurgeon or the power he wielded on enforcing a decision, as no participants sought out the neurosurgeon's professional credentials. The decision to have the awake craniotomy, based on the *relationship with the neurosurgeon,* was best articulated by Rachel, Emma and Ben:

> Rachel*:* ...I just said to Dr. James [neurosurgeon], I trust you whatever you think...if there wasn't that there [the trust] I think I would have questioned him a lot more

Emma: ...If it wasn't somebody [referring to the neurosurgeon] like that I would have been possibly at least a bit more reluctant or perhaps wouldn't, maybe try to strive for somebody that I did feel happy with

Ben: ...If I wasn't comfortable [with the neurosurgeon] I wouldn't have done it in the first place...he [neurosurgeon] was more than relaxed about it, so you know I think that puts you at ease as well as a patient, you know if you've got faith in your surgeon

Participants believed that they were placing their lives in the hands of the neurosurgeon. Therefore it was interpreted that the *relationship with the neurosurgeon* was an extension of the *self-preservation* strategies described above. By giving the responsibility of deciding whether to go ahead with the awake craniotomy to the neurosurgeon, participants were avoiding facing the implications of the decision themselves.

Implications of self-preservation strategies. At the time of awake craniotomy the utilisation of *self-preservation* strategies by participants appeared to have implications. The strategies appeared to have inhibited the participants' ability to comprehend the reality of the situation until immediately prior to the awake craniotomy. Jen and Craig articulated an increase in anxiety when admitted to hospital for the awake craniotomy:

Jen: ... I felt very nervous, yeh, felt very nervous, very anxious and just really, I think it was quite surreal, I felt like it wasn't really happening, I think, umm, cuz I sort of laid there on my own, it's all quiet and its dark and yeh sort of feeling like, a sense of being on my own, and nobody with me

Craig: ...I probably started to feel a little bit sort of anxious more than nervous once I was in hospital cos it was then, this is actually going to happen now, I'm actually here, it's not a day written in a letter that I've got to turn up for, I'm actually sat here waiting

Emma extended on this and struggled to reason why the reality of the operation was suddenly upon her at this point:

Emma: ...and then I was sort of lying in the umm it just hit me, when I was sort of it's probably cos probably cos It's one of the only times I was ever really on my own, sort of lying there waiting to go in, I thought oh God [whisper]

The above quote from Emma demonstrates how she drew her own conclusion that it had been the only time she had been on her own and not keeping herself busy. In doing so she alluded to how the *self-preservation* strategies adopted during preparation impacted on her immediately prior to the operation.

Operation environment

The *relationship with the neurosurgeon* described in the above theme was made explicit when considering the *operation environment*. It was understood that participants found being awake during the operation "bizarre":

> Jen: ...you're aware that you are awake but you can't, you can't reason the fact that you are, very very bizarre

> *Craig*: ...It's a strange thing cos they've got control of you, but at the time, it didn't bother me, it didn't worry me

All participants described the operating space:

> Jen: ... all your aware of is your in this room, which is bright, I remember all these lights, it's very white, very clean obviously, umm

> Craig: ...but it was like walking into a sunlit room there was, it was white, it was airy, it was light, there was see everything, hear everything, and you just felt, big and airy, there was no, no sort of pretence to it

Some participants discussed the sounds in the awake craniotomy:

> Craig: ... they were screws going in and I could hear the screws going in, through the, against the bone, cos it was all echoing very strange sounds

> Rachel: ...I couldn't see anything orr I mean I could hear things but it just sounded like a dentist sorta drill

Rachel discussed the head frame as her only bad memory:

> Rachel: ... the worst thing of the whole operation was y'know the frame that holds ya head... they had to inject me with anaesthetic...that's the only bad memory I've got from it

Although bizarre, participants appeared to find the awake craniotomy a fascinating and a pleasant experience:

> Jo: ...I remember it being quite a pleasant experience, and certainly not frightening in any way

> Sundeep: ...I felt very comfortable and psychologically I didn't feel any issues at all...it was just fine

> Craig: ... it was sort of quite a little pleasant experience, most bizarre way of putting it, there was no, but there was no this is horrible

Participants reflected on this particularly in relation to them being the centre of attention in the operating space:

> Craig: ... you didn't feel sort of the odd one out of it all, you were sort of you were the centre of everything and everything did work around you and for you, it was quite weird but it was nice

To control the emotion felt during the awake craniotomy, provoked by finding the awake craniotomy bizarre, participants appeared to rely on their *self-preservation* strategies:

> Emma: ...I think you try not to sort of think...about what's really going on then it doesn't, y'know it's just you can't feel anything, you can't see anything

> Ben: ...I had the green covers around me, you know I wasn't even trying to have a sneaky peak, I was focussing straight ahead

> Jen: ...You've built up that relationship with him [neurosurgeon], and when you wake up and you hear that familiar voice, in a way, it relaxes you, I don't know if that's the right word, it does, I suppose it reassures you

This may have been a combination of participants adopting *self-preservation strategies*, for example Jen described drawing on the relationship she had developed with the neurosurgeon, or it could be attributed to the neurosurgical team strategically adopting distraction strategies throughout the awake craniotomy:

Emma: ...they were all quite jokey, jovial they were all talking to me all the time and it seemed to go really quickly, I wasn't thinking oh God when is this going to be over?...they're talking to you, that kept me occupied

Craig: ...The fact their talking to me there was always sort of [pause] how are you, can you see anything moving, can you still move your fingers, can you still wiggle your toes, how's your leg, how's your arms, can you feel anything in your face, there was no sort of my lying there awake in complete silence, they either were asking me what was going on or they were reassuring me

It was felt that if the *relationship with the neurosurgeon* did not exist, or self-preservation strategies were not adopted or facilitated by the neurosurgical team, participants may have focused more on the bizarre aspects of the operation and potentially suffered increased apprehension levels. Emma articulates this point:

Emma: ...I think he if he had not made me feel comfortable and just and y'know quite relaxed about it all I would have been y'know different

[See 4.1 for further quotes, additional thoughts and an addition to the operation environment theme]

Information

The theme information encompasses ideas presented by participants about the lack of concrete information given to them prior to the awake craniotomy. Participants described the impact this had on their ability to relay information back to family and friends, understand the operation procedure and understand the potential consequences. Although this was the case no participants reported seeking out additional concrete information prior to the awake craniotomy, this was interpreted as associated to their relationship with the neurosurgeon.

Most participants reflected on the lack of concrete *information* available to them during their experience of awake craniotomy as unsatisfactory:

Jen: ...there wasn't a lot of information I felt was available to find out exactly what was going to be done

Participants discussed feeling that adequate information was not available to give to family and friends:

> Rachel: ...because a lot of questions they [family and friends] ask you, you can't answer so you, because you don't know yourself, so to have just an information pack, it would've been so much easier to just come home when there all, everyone wants to ask you the same question 10 times, to just drop a leaflet in the hand and just say read that

Jen discussed that a lack of concrete information impacted her understanding during the awake craniotomy:

> Jen: ...maybe a bit of a not quite understood what, what you know, I didn't quite fully understand what they wanted to do [in the awake craniotomy]

Craig and Ben discussed that a lack of concrete information impacted on their understanding of the expected outcomes:

> Craig: ....we [Craig and his wife] didn't realise at the time but its only since our last meeting with the consultant [neurosurgeon] that although a tumour on your brain can cause you to have an epileptic fit, the scar tissue from having a tumour and having the operation, is as effective if not more effective at causing fits

> Ben: ... wasn't until I went back and saw the Dr. Carr [the anaesthetist] he explained the epileptic network but that was never explained to me before the op [awake craniotomy]...

Given the participants' retrospective dissatisfaction with the lack of concrete information, yet their failure to seek out concrete information at the time, it was interpreted that participants utilised their *relationship with the neurosurgeon* as a compensation strategy for concrete information:

> Emma: ...but Mr. Johns [neurosurgeon] was lovely and just totally put me at ease

> Jen: ...I'd had quite a few appointments with him [neurosurgeon] and it was quite in depth, go through quite a lot with you

Jo summarised this point:

> Jo: ... he gave lots of information...umm so yeah I just kind of stuck with y'know what they said

Emma articulated the impact that the *relationship with the neurosurgeon* had on her need to seek out different opinions or more information:

> Emma: ...I mean to be fair I felt comfortable with him [neurosurgeon] from the word go, I mean Ben [husband] sort of said y'know do you want to look for different surgeons this that and the other, somebody in [a different county], I said to be honest I can't be arsed to trail around, I said I'm, not feeling the best, I just want to get it over with

In this extract Emma discussed how the relationship she had developed with the neurosurgeon stopped her from seeking out information and opinion from elsewhere. In doing this Emma alluded to her utilisation of *self-preservation* strategies, for example using the relationship with the neurosurgeon and avoiding thinking about the upcoming awake craniotomy. Emma also alluded to her displeasure with her husband seeking *information* from elsewhere. It appeared that due to his lack of certainty or understanding he was continually attempting to engage Emma with questions and new *information*. Therefore on one hand, a lack of information appeared to facilitate the self-preservation strategies of participants through facilitating their avoidance of *information*. However, on the other hand as participants did not have concrete *information* to share with their family and friends their self-preservation strategies appeared to be continually challenged.

[See 4.2 for addition to the information subtheme]

Discussion

Analysis of data revealed three superordinate themes: *self-preservation*, *operation environment* and *information.* The superordinate themes were interpreted as embedded in a core theme: *relationship with the neurosurgeon.* In line with previous research, the current study supports that participants were satisfied with[17,43,63] , and tolerant of[71,74,90] the awake craniotomy experience.

Core theme: relationship with the neurosurgeon

The relationship with the neurosurgeon was reported as crucial to the patient experience of awake craniotomy. Although the importance of the neurosurgeon has been alluded to in a previous thematic study exploring the patient experience of awake craniotomy in Canada[43], the emphasis placed on the core theme in the current study is novel to the awake craniotomy literature. The importance of the *relationship with the neurosurgeon* is consistent with a wider emphasis on the surgeon-patient[2], neurosurgical team-patient[55] and clinician-patient[12] relationship. The emphasis on the surgeon[2] is thought to be attributable to the fact that more operations are now conducted awake, involving the surgeon in building a relationship, and communicating with the patient. In addition research has reported that participants who were awake during an operation felt that one of the most important aspects of their care was their interactions with the neurosurgical team[55]. Finally the emphasis on the clinician[12] is reported in back pain research discussing the importance of social and contextual factors, such as the clinician-patient relationship, when patients are making treatment decisions[12].

Through the emphasis on the *relationship with the neurosurgeon* in the current study neurosurgical[37,70], medical[37] and low grade glioma[70] research is supported that suggests that patients who are listened to, treated respectfully and shown concern feel more secure and able to participate[70], have more psychological benefits[37] and are more satisfied[70]. In contrast, research proposing that neurosurgeons display fewer therapeutic characteristics than other medical disciplines[36,72] is questioned.

Although the *relationship with the neurosurgeon* appears crucial to the patient experience in the current study a need is highlighted for all neurosurgeons to be facilitating trust and mutual respect. This places pressure on upcoming and practicing neurosurgeons to develop relationships with patients through the use of therapeutic skills[2] and through allowing the patient time to develop a relationship with the surgical team prior to an operation, reported as important in awake glioma surgery[38]. The importance of facilitating the development of therapeutic skills is emphasised when considering research reporting that surgeons who were completing their training overemphasised their own communication skills when asked to self-rate[33]. This was in comparison to clinician rating scales given to their patients.

To develop therapeutic skills the University of Massachusetts has developed a human factors curriculum for upcoming neurosurgeons[50]. This training develops skills such as patient communication, empathy and caring, educating the patient and working with difficult personality styles. This is clearly directed towards the neurosurgeon-patient relationship and has reported positive outcomes with regard to increased empathy. Similarly clinicians in primary care settings are required to undergo mandatory empathy training[75]. This is a feasible option for neurosurgeons and discrete but focused sessions of training, utilising patient input, could impact on a surgeon's insight in to their own communication skills and subsequently lead to improvement in patient experience. This is also supported by research in to nursing communication[48].

Self-preservation

The first superordinate theme, *self-preservation*, illustrates how participants utilised strategies, such as avoidance, distraction, external focus and humour, to protect them from thinking about the upcoming awake craniotomy and the potential consequences associated with it. Using *self-preservation* strategies in this way was discussed briefly within a theme, 'preoperative concerns: working out the intraoperative role' (p. 168), in a previous phenomenological study exploring the patient experience of awake craniotomy in Italy[71]. The authors in this study[71] placed less emphasis on self-preservation strategies than the current study. They briefly reported that the evening prior to the awake

craniotomy participants wanted to keep busy or distract themselves to cope with their situation. Aside from this the theme *self-preservation* does not directly support any previously identified themes on the experience of awake craniotomy.

In contrast to the current study, previous qualitative studies[43,71] exploring the patient experience of awake craniotomy have identified self preservation as the choice to have the awake craniotomy. This relates to the participant choosing to decrease the probability of damage, defect or disability from the tumour, or defeat the tumour, through having the awake craniotomy.

The use of coping strategies for self-preservation, as in the current study, has been widely discussed. Coping has been defined as a response to a demand which is placing pressure on a person's usual resources[22]. Traditionally coping strategies are split in to emotion-focused coping: where participants act and think in an attempt to process their emotions, and problem-focused coping: where participants believe that they can change their situation by acting upon it[51]. Exploring coping strategies is complex as individuals may use them synonymously or alternately[11,28,83]. The impact of adopting coping strategies can lead to adaptation to a new situation[51]. However if the coping strategies are dysfunctional patients may struggle to adapt[9,29] and their quality of life may suffer[29]. There is limited literature exploring coping strategies for the purpose of *self-preservation* prior to any type of surgery, or for brain tumour populations[79]. Findings consistent with and contrasting to the current study will be discussed for each strategy of *self-preservation.*

Avoidance. The finding that participants use avoidance as a way to cope with their upcoming awake craniotomy supports previous research on participant preparation for surgical procedures. One study asked 80 participants with Parkinson's disease awaiting neurosurgery to complete a coping strategy questionnaire[15]. The authors reported that participants are most likely to adopt behavioural strategies such as avoidance. The use of avoidance was also reported in patients awaiting heart transplants[7]. Although the findings of these studies are similar to the current study they were conducted on people with different conditions. For example, patients with

Parkinson's disease may have a different disease process to a brain tumour population. Thus, where surgery may be the first choice of treatment for brain tumour patients[65,68], it is most often used in Parkinson's disease populations where drug therapy is no longer effective[82]. This may alter the coping strategies adopted by participants.

The use of avoidance as a coping strategy has also been reported in brain tumour and oncology populations. One study reported individuals as "refraining from and avoiding"(p. 728)[26] when diagnosed with a low grade brain tumour. In addition a Korean study suggested that patients with cancer are more likely to use avoidance as their primary coping strategy[45]. Although these studies more closely resemble the disease process of the awake craniotomy population, differences may exist in the coping strategies of cancer patients who are not offered awake craniotomy as a treatment option. Neither study discussed specifies the options available to patients at the time of coping strategy exploration however one study alluded to medication as treatment for their sample population[26].

When considering the implications of using avoidance as a coping strategy contrasting literature exists. Traditional coping literature reports that avoidance can maintain anxiety disorders[3,25] and could be a risk factor for depressive symptoms. This does not appear to be the case in neurosurgery. When considering self-preservation or coping literature differing effects according to the control individuals feel they have of the situation should be considered[15,24,88]. Literature suggests that where a situation is uncontrollable (such as the awake craniotomy) individuals may benefit more from behavioural strategies such as avoidance[15,24,88]. Two studies have reported that avoidance in preparation for neurosurgery can have a positive effect on depressive symptoms[15,24]. In the current study it was felt that the adoption of self-preservation strategies prior to the awake craniotomy meant that participants' only realised that the operation was upon them immediately prior to the operation, suggesting that the use of action-based strategies such as avoidance helped to contain their levels of apprehension prior to the awake craniotomy. This emphasises the importance of considering the specific situation when generalising coping literature.

Humour and distraction. The use of humour and distraction as *self-preservation* strategies will be discussed together. This is due to the lack of research referring to the use of distraction as a coping strategy prior to neurosurgery or in the face of a life threatening event. In this respect it was anticipated that distraction may be amalgamated with alternative coping strategies in the literature. For example distraction has been referred to alongside humour and irony[1].

Humour has been described as "a protective cushion against the jagged impact of stressful experiences" (p. 232)[42]. The use of humour in the current study is not discussed in previous research exploring coping strategies for neurosurgery. However it is consistent with literature reporting the use of distraction, irony and humour by brain tumour patients[1], by patients facing life-threatening illness[28,61] and again when exploring the coping strategies of different populations such as diabetes[86].

The use of humour has been proposed to have positive effects on patients' well-being[31]. Research suggests that humour can be a key part of a relationship and if used tactfully by clinicians it can have benefits for oncology patients[31]. Sense of humour could also facilitate coping and adjustment in everyday stressful life events[46] and significantly reduce levels of stress[54].

Religion. The findings from one participant in the current study are consistent with reports that when people are faced with stressful life events, if they have a religious orientation, this is often used as a coping strategy[84]. The use of religion as a coping strategy is thought to have contrasting effects. A systematic review of the literature exploring the potential benefits or harm related to adopting religious or spiritual coping strategies concluded that due to methodological constraints in evidence suggesting that religious coping could be harmful, the potential benefits or harm caused by this is unknown[84].

Although this is the case, a study not included in the systematic review reported an association between religious coping and improved quality of life for participants with advanced cancer[80]. The authors concluded that positive religious coping, for example drawing on religious beliefs, was associated with a better overall quality of life[80]. However, negative religious coping, such as

blaming a God, is related to poorer quality of life[80]. This supports past research suggesting that religion can help patients face the adjustment process, sustain self-esteem and gain a sense of meaning[30,84].

External Focus. The current findings show support for a study on the coping strategies of patients with Parkinson's disease[15]. In addition to findings on avoidance, the authors reported that where participants were faced with an acute stressor, for example the decision to have neurosurgery, they adopted strategies such as seeking out enjoyable activities[15]. This is similar to participants in the current study who reported turning to their favourite sport or to spending time with their families. Adopting such activities is thought to be associated with better mood[15].

Treatment decision making. The findings in the current study suggest that participants rely on the neurosurgeon to make the treatment decision. Thus they use their relationship with the neurosurgeon as a *self-preservation* strategy. This is consistent with research reporting that following advice was a main strategy used by cancer patients when making a treatment decision[72] and on a broader scale the Cancer Guidance Subgroup[10] reported that lung cancer patients did not want to be part of the decision making process.

Implications exist for strategic planning in the NHS regarding the utilisation of the *relationship with the neurosurgeon* as a self-preservation strategy to make a treatment decision. Thus, the NHS is currently promoting patient choice and autonomy in treatment decision making. The current study lends support to literature claiming that patients would prefer clinicians to make decisions on their behalf, particularly where the decision was based on a life threatening illness[23]. However, implications of avoiding treatment decisions have been reported as impacting on a patient's ability to cope[72].

Operation environment

The second superordinate theme, *operation environment,* supports previous research suggesting that participants are less concerned about the awake craniotomy procedure, in comparison to other parts of the experience[43]. It also demonstrates support for previous research suggesting that participants' find

staying awake a positive aspect of any operation[22]. One study reported that during orthopaedic surgery patients reported staying awake as a positive aspect[22]. A second study[41] concluded that the most stressful part of awake caesarean surgery was immediately prior to the operation when it was imminent and a final study[8] reported that 80% of participants would have awake surgery again. In contrast, and in support of an Italian study exploring the awake craniotomy[71], literature exists stating the negative experience of the patient during awake operations. Studies of other operations including caesareans[13], hip replacements[34] and elective surgery[39] reported that participants became distressed during the procedure due to the sounds of the operation and the physical aspects of the operating space.

The contrast between the current study and the previous literature could be attributed to the time in which the participants were asked to provide data. The phenomenological study[71] exploring the patient experience of awake craniotomy, asked participants immediately following awake craniotomy to describe their experience. However the thematic study[43] asked participants up to two weeks following surgery and the current study asked up to four years following surgery. This could account for the differences in recollections by participants.

The participants in the current study described the operation as bizarre yet pleasant. Such bizarre or surreal interpretations are consistent with previous awake craniotomy literature[43]. The pleasant aspect of the experience was partly attributed to the participants' *relationship with the neurosurgeon* in the current study. It was interpreted that participants utilised their *relationship with the neurosurgeon* to contain their apprehension during the procedure. Again, the utility of the *relationship with the neurosurgeon* in this way is novel to this awake craniotomy study. However it supports previous research exploring awake caesarean surgery[13], the emphasis placed on the surgeon-patient relationship[2] and research recognising the importance of the therapeutic relationship in psychotherapies[47]. Such research proposes that if the participants develop a good relationship with the neurosurgeon, they may develop more trust and confidence in the neurosurgeon[2], potentially leading to a better experience with less distress.

As well as the *relationship with the neurosurgeon* it was interpreted that participant apprehension was contained due to use of distraction or avoidance techniques by participants and the neurosurgical team during the awake craniotomy. This is consistent with research proposing that distraction techniques during awake operations can be beneficial for patients. For example, studies have reported that therapeutic hand massage[44], hand stroking[67], intra operative music[56] and viewing a video compact disc[62] can significantly reduce participant anxiety during neurosurgery. Although beneficial these studies were conducted on cataract, spinal and elective patients respectively. Thus none of these operations required the participant to complete an awake task during the procedure.

Information

The final superordinate theme, *information,* illustrates how participants accepted face-to-face consultation sessions as adequate to gather *information* about awake craniotomy. However, when retrospectively considering *information* provision, participants reported dissatisfaction, particularly with respect to concrete *information*. It was interpreted that at the time of awake craniotomy participants avoided seeking further *information* as a *self-preservation* strategy. Instead participants utilised their *relationship with the neurosurgeon* to compensate for further information. Participants appeared to be containing their apprehension through blocking any further knowledge of the awake craniotomy procedure.

Avoidance of information is consistent with research suggesting that patients with low grade brain tumours avoid information[26]. However it is inconsistent with a previous qualitative study[43] which reported that participants who have experienced an awake craniotomy seek information through the neurosurgery team as well as the internet. Not receiving adequate concrete *information* is consistent with previous research that has found that patients are unhappy with the amount of information they are given[59] as well as clinical guidelines

recommending a need for improvement of information provision in neurosurgery departments[19-21].

The implications of the lack of concrete information, or relying on the *relationship with the neurosurgeon*, span across the awake craniotomy experience. Following leaving the consultation space participants were compromised by their ability to understand the awake craniotomy, their ability to discuss the procedure with friends and family and their ability to understand the potential consequences. This is consistent with awake craniotomy research reporting that not having information affects the participants' understanding during the operation[68]. In contrast to previous research it did not appear that the lack of adequate information affected the participants perception of the experience[53] or levels of anxiety[40,53,66], instead the lack of information may have improved the participant experience through facilitated avoidance *[See 5.3 in extended paper for a discussion on information]*

Strengths and limitations

The current study is the first in the UK to explore the experience of awake craniotomy and the first to explore this using IPA methodology. This extends the small evidence base, adding to neurosurgeon understanding, as well as, for the first time in awake craniotomy studies, placing emphasis on the neurosurgeon to develop skills to facilitate their relationship with the patient.

A limitation of the study was the opt-in procedure used to recruit participants. No attempt was made to find out the reasons why potential participants chose not to take part and it is unclear if the participants who did not choose to take part had a more intolerable, or less satisfactory experience. This supports findings in previous awake craniotomy studies[17,32,71,90] and is important to consider when attempting to transfer findings across populations.

A further potential limitation of the study is that all participants were recruited from a single neurosurgery department. This could impact on the ability to transfer the findings to wider populations. However, IPA[77] cautions against attempting to transfer findings from small, purposive samples. Therefore it could be argued that recruiting from a number of neurosurgery departments

would not have added to the transferability. Instead the findings of the study can be used to inform neurosurgery departments about their practice. In addition, data was collected from participants about their experience of awake craniotomy up to four years following the experience. Clinicians have reported observations that perceptions of the procedure change over time[17]. Although IPA[77] proposes that it is the experience itself that is of primary interest and the time frame is insignificant, having differing time frames to previous studies makes it more difficult to draw comparisons across the studies. *[See 5.5 for further discussion on the strengths and limitations of the current study]*

Implications

The findings of this study add to previous awake craniotomy research through their emphasis on the *relationship with the neurosurgeon.* This is consistent with literature outside of the awake craniotomy experience[2]. It is important to consider the effect this may have on the neurosurgeon. Thus, if the neurosurgeon does not have the skills to build the relationship, and the patient does not understand the procedure, the current findings amalgamated with past literature suggest that apprehension prior to the experience, and during the awake craniotomy procedure may rise[5,57,74,90]. In order to fulfil this role neurosurgeons may require further training in communication and empathy[2,50,69] and subsequently research needs to be conducted to inform this training.

In primary care, research has been conducted to explore the relationship between communication behaviours and patient outcomes. This has included patient satisfaction[73]. Future research could focus on the core theme in this way. Such research is supported by authors who discuss the excess of this type of research in primary care but the lack of it in surgery[65]. Future research could also replicate an observational study conducted[65] but with neurosurgeons. This study aimed to capture interactions between physician and patient through observing usual clinical practice. This would add to the literature base for surgeons as well as influencing more positive awake craniotomy experiences. Given the increasing focus on the neurosurgeon to develop relationships such research is of high importance. Conducting further research will ensure the relevance and validity of recommendations for

improving communication skills rather than generalising from an alternative discipline.

Further to the implications on the neurosurgeon the findings also have implications for neurosurgery departments. Participants in the current study reported a satisfaction with the consultation meeting at the time of awake craniotomy. However it appears that, although participants were satisfied, a lack of concrete information compromised their understanding of the awake craniotomy procedure, the information they had to communicate to family and friends and their understanding of the expected outcomes of the operation. To help patients make an informed decision further research is required on the preferences of brain tumour patients regarding *information* provision[69]. In the mean time *information* must consist of both face-to-face consultations and written *information*. Alternatively, as recommended in a recent NHS report for patients with lung cancer, consultation sessions could be recorded for patients[10]. Either way, information should outline the advantages and disadvantages of their decision to have the awake craniotomy and in line with the findings in the current study, could include a section on effective coping strategies. Once the information was available participants could then decide if and how they wanted to use the information, potentially improving patient understanding of the procedure, facilitating their families in understanding their experience and helping contain apprehension for awake craniotomy patients.

To generate research on coping strategies the contrast between controllable and uncontrollable situations and their link to coping strategies also warrants further investigation. With regards to the current study it is suggested that further research should explore the use of coping strategies by brain tumour patients prior to and during the awake craniotomy procedure. This would provide an evidence base specific to the awake craniotomy population. The effects of such evidence could help to generate ideas for the facilitation of coping for prospective patients, potentially improving the awake craniotomy experience[15].

Conclusions

A positive step forward has been taken by this research to add to the understanding of the patient experience of awake craniotomy: brain tumour diagnosis to discharge. The current study extends on findings reported in previous research through the core theme: *relationship with the neurosurgeon*. It was interpreted that this relationship had an impact on the decision to have the awake craniotomy, on the acceptance of the *information* given and on participants' levels of apprehension during the operation. Implications for neurosurgery departments include more consideration for the skills of the neurosurgeon, a more in-depth understanding of *self-preservation* strategies for patients and better provision of written *information*. Being aware of the implications may facilitate positive awake craniotomy experiences in the future, as well as helping future patients to understand how to prepare for the operation they are about to undertake. *[See 5.7 in extended paper for extended conclusions]*

References

1. Adelbratt S, Strang P: Death anxiety in brain tumour patients and their spouses. **Journal of palliative medicine 14(6):** 499-507, 2000

2. Axelrod DA, Door Gould S: Maintaining trust in the surgeon-patient relationship: challenges for the new millennium. **Archives of surgery 135:** 55-61, 2000

3. Behar E, DiMarco ID, Hekler B, Mohlman J, Staples AM: Current theoretical models of generalised anxiety disorder (GAD): conceptual review and treatment implications. **Journal of anxiety disorders 38(8):** 1011-1023, 2009

4. Bernstein M: Outpatient craniotomy for brain tumor: a pilot feasibility study in 46 patients. **The Canadian journal of neurological sciences 28(2):** 120-124, 2001

5. Black S: Comments. **Neurosurgery 42:** 35, 1998

6. Blanshard HJ, Chung F, Manninen PH, Taylor MD, Bernstein M: Awake craniotomy for removal of intracranial tumour: considerations for early discharge. **Anaesthesia and analgesia 92:** 89-94, 2001

7. Burker EJ, Madan A, Evon D, Finkel JB, Mill MR: Educational level, coping, and psychological and physical aspects of quality of life in heart transplant candidates. **Clinical transplantation 23(2):** 233-240, 2009

8. Callesen T, Bech, K, Kehlet H: One-thousand consecutive inguinal hernia repars under unmonitored local anaesthesia. **Anesthesia and analgesia 93(6):** 1373-1376, 2001

9. Canam C: Common adaptive forms facing parents of children with chronic conditions. **Journal of advanced nursing 12:** 671-676, 1993

10. Cancer Guidance Subgroup of the Clinical Outcomes Group: **Improving outcomes in lung cancer – the research evidence.** Leeds, England: NHS Executive, 1998

11. Carver CS, Pozo C, Harris SD, Noriega V, Scheier MF, Robinson DS et al: How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer. **Journal of personality and social psychology 65(2):** 375-390, 1993

12. Chibnall JT, Tait RC: Observer perceptions of low back pain: Effects of pain report and other contextual factors. **Journal of applied social psychology 25:** 418–439, 1995

13. Chit Ying L, Levy V, Shan CO, Wing Hung T, Kit Wah W: A qualitative study of the perceptions of Hong Kong Chinese women during caesarean section under regional anaesthesia. **Midwifery 17(2):** 115 -122, 2001

14. Costello TG, Cormac JR: Anaesthesia for awake craniotomy: a modern approach. **Journal of clinical neuroscience 11(1):** 16-19, 2004

15. Croyle KL, Troster AL, Fields JA, Straits-Troster KA, Lyons KE, Pahwa R: Presurgical coping, depression, and quality of life in persons with Parkinson's disease. **Journal of clinical psychology in medical settings 10(2):** 101-107, 2003

16. Crumlish CM: Coping and emotional response in cardiac surgery patients. **Western journal of nursing research 16(1):** 57-68, 1994

17. Danks RA, Rogers M, Aglio LS, Gugino LD, Black PM: Patient tolerance of craniotomy performed with the patient under local anaesthesia and monitored conscious sedation. **Neurosurgery 42(1):** 28-36, 1998

18. Danks RA, Aglio LS, Gugino LD, Black PM: Craniotomy under local anaesthesia and monitored conscious sedation for the resection of tumors involving eloquent cortex. **Journal of neuro-oncology 49***:* 131-139, 2000

19. Davies E, Hopkins A: Good practice in the management of adults with malignant cerebral glioma: clinical guidelines. **British journal of neurosurgery 11:** 318– 330, 1997

20. Davies E, Hopkins A: **Improving care for patients with malignant cerebral glioma.** London: Royal College of Physicians, 1997b

21. Davies E, Higginson IJ: Communication, information and support for adults with malignant cerebral glioma: a systematic literature review. **Supportive care in cancer 11**: 21-29, 2003

22. De Andres J, Valia JC, Gil A, Bolinches R: Predictors of patient satisfaction with regional anaesthesia. **Regional anaesthesia 20(6):** 498-505, 1995

23. Degner LF, Sloan JA: Decision making during serious illness: what role to patients really want to play? **Journal of clinical epidemiology 45(2):** 941-950, 1992

24. DeGroot KI, Boeke S, Bonke B, Passchier J: A re-evaluation of the adaptiveness of avoidant and vigilant coping with surgery. **Psychology and health 12:** 711–717, 1997

25. Dymond S, Roche B: A contemporary behaviour analysis of anxiety and avoidance. **The behaviour analyst 32(1):** 7-27, 2009

26. Edvardsson T, Ahlstrom G: Illness-related problems and coping among persons with low-grade glioma. **Psycho-oncology 14(9):** 728-737, 2005

27. Fisher JL, Schwartzbaum JA, Wrensch M, Wiemels JL: Epidemiology of brain tumors. **Neurologic clinics 24(4):** 867-890, 2007

28. Folkman S, Moskowitz JT: Positive affect and the other side of coping. **American psychologist 55:** 647–654, 2000

29. Folkman S, Moskowitz JT: Coping: pitfalls and promise**. Annual review of psychology 55:** 745-774, 2004

30. Fox RB: Religious identity, religious practices, and spiritual coping in adults undergoing treatment for cancer. **Dissertation abstracts: section b: the sciences and engineering 62(10):** 4763, 2002

31. Gilligan B: A positive coping strategy. Humour in the oncology settings. **Professional nurse 8(4):** 231-223, 1993

32. Goebel S, Nabavi A, Schubert S, Mehdorn HM: Patient perception of combined awake brain tumor surgery and intraoperative 1.5T magnetic resonance imaging: the Kiel experience. **Neurosurgery 67(3):** 594-600, 2010

33. Goldstein AP, Goedhart A: The use of structured learning for empathy enhancement in paraprofessional psychotherapists. **Journal of community psychology 1:** 168–173, 1973

34. Hankela S, Kiikkala I: Intraoperative nursing care as experienced by surgical patients. **American operating room nurses' journal 63(2):** 435-442, 1996

35. Hassett JM, Zinnerstrom K, Nawatniak RH, Schimpfhauser F, Dayton MT: Utilization of standardized patients to evaluate clinical and interpersonal skills of surgical residents. **Surgery 140(4):** 633-639, 2006

36. Hojat M, Mangione S, Gonnella JS, Nasca T, Veloski JJ, Kane G: Empathy in medical education and patient care (letter). **Academic medicine 76**: 669, 2001

37. Hojat M, Gonnella JS, Nasca TJ, Mangione S, Vergare M, Magee M: Physician empathy: definition, components, measurement, and relationship to gender and specialty. **American journal of psychiatry159(9):** 1563-1569, 2002

38. Jaaskelainen J, Randell T: Awake craniotomy in glioma surgery. **Acta NeurchirWien 88:** 31-35, 2003

39. Jakobsen VH, Fagermoen MS: Environmental factors in the operating theatre and their impact on patients' preoperative anxiety. **Tidsskrift for skepleieforskning 7(4):** 4–17, 2005

40. Johansson K, Nuutila L, Virtanen H, Katajisto J, Salantera S: Pre-operative education for orthopaedic patients: systematic review. **Journal of advanced nursing 50(2):** 212–223, 2005

41. Kennedy BW, Thorp JM, Fitch W, Millar K: The theatre environment and the awake patient. **Journal of obstetrics and gynaecology 12**: 407–411, 1992

42. Kess JF: Review of humour: The psychology of living buoyantly. **Canadian psychology 42(3):** 232-234, 2003

43. Khu KJ, Doglietto F, Radovanovic I, Taleb F, Mendelsohn D, Radovanovic I et al: Patient's perceptions of awake and outpatient craniotomy for brain tumour: a qualitative study. **Journal of neurosurgery 10:** 1-5, 2009

44. Kim MS, Cho KS, Woo HM, Kim JH: Effects of hand massage on anxiety in cataract surgery using local anaesthesia. **Journal of cataract and refractive surgery27(6**):884–890, 2001

45. Kim HS, Yeom HA, Seo YS, Kim NC, Yoo YS: Stress and coping strategies of patients with cancer: a Korean study. **Cancer nursing 25(6):** 425-431, 2002

46. Kuiper NA, Martin RA, Olinger LJ: Coping humour, stress, and cognitive appraisals. **Canadian journal of behavioural science 25(1):** 81-96, 1993

47. Lambert MJ, Barley DE: Research Summary on the therapeutic relationship and psychotherapy outcome. **Psychotherapy 38(4):** 357-361, 2001

48. LaMonica EL, Carew DK, Winder AE, Bernazza-Hasse AM, Blanchard KH: Empathy training as the major thrust of a staff development program. **Nursing research 25**: 447–451, 1976

49. Lanier WL: Brain tumour resection in the awake patient. **Mayo clinical proceedings 76:** 670-672, 2001

50. Larkin AC, Cahan MA, Whalen G, Hatem D, Starr S, Haley HL et al: Human emotion and response in surgery (HEARS): A simulation-based curriculum for communication skills, systems-based practice, and professionalism in surgical residency training. **Journal of American college of surgeons 211(2):** 285-292, 2010

51. Lazarus RS, Folkman S: **Stress, appraisal and coping.** New York: Springer, 1984

52. Lazarus R: Coping theory and research: past, present and future.

Psychosomatic medicine 53: 234–37, 1993

53. Lee A, Chui PT, Gin T: Educating patients about anaesthesia: a systematic review of randomized controlled trials of media-based interventions.

Anaesthesia and analgesia 96(5): 1424–1431, 2003

54. Lefcourt HM: **Humor: The psychology of living buoyantly**. New York: Kluwer Academic / Plenum Publishers, 2001

55. Leinonen T, Leino-Kilpi H, Jouko K: The quality of intraoperative nursing care: the patient's perspective. **Journal of advanced nursing 24(4):** 843–852, 1996

56. Lepage C, Drolet P, Girard M, Grenier Y, DeGagne R: Music decreases sedative requirements during spinal anesthesia. **Anesthesia and analagesia 93(4):912**–916, 2001

57. Lepola I, Taljamo M, Aho R, Louet T: Being a brain tumour patient: a descriptive study of patient experiences. **Journal of neuroscience nursing 33(3):** 143-146, 2001

58. Levinson W, Chaumenton N: Communication between surgeons and patients in routine office visits. **Surgery 125**: 127-134, 1999

59. Lidstone V, Butters E, Seed PT, Sinnott C, Beynon T, Richards M: Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. **Palliative medicine 17:** 588-595, 2003

60. Lincoln YS, Guba EG: **Naturalistic enquiry.** Newbury Park, CA: Sage Publications, 1985

61. Livneh H: Psychosocial adaptation to cancer: The role of coping strategies. **The journal of rehabilitation 66(2):** 40–49, 2000

62. Man AK, Yap JC, Kwan SY, Suen KL, Yip HS, Chen PP: The effect of intra-operative video on patient anxiety. **Anaesthesia 58(1):** 64–68, 2003

63. Manninen PH, Balki M, Lukitto K, Bernstein M: Patient satisfaction with awake craniotomy of tumour surgery: a comparison of remifentanil and fentanyl in conjunction with propofol. **Neurosurgical anaesthesia 102:** 237-242, 2006

64. McDougall R, Rosenfeld J, Wrennall J, Harvey AS: Awake craniotomy in an adolescent. **Anaesthesia and intensive care 29:** 423–425, 2001

65. Meyer FB, Bates LM, Goerss SJ, Friedman JA, Windschiti WL, Duffy JR et al: Awake craniotomy for aggressive resection of primary gliomas located in eloquent brain. **Mayo clinic proceedings 76:** 677-687, 2001

66. McKenna D: A focus on the five senses of the day surgery patient: quality assurance initiative. **Ambulatory surgery 5(2):** 61–65, 1997

67. Moon JS, Cho KS: The effects of handholding on anxiety in cataract surgery patients under local anaesthesia. **Journal of advanced nursing 35(3):** 407–415, 2001

68. Moritz-Gasser S, Duffau H: Psychological consequences of awake brain tumour surgery. **Psycho-oncologie 4(2):** 96-102, 2010

69. National Institute for Clinical Excellence. **Improving outcomes for people with brain and other CNS tumours – the manual**. NICE cancer service guidance, 2006

70. Nightingale SD, Yarnold PR, Greenberg MS: Sympathy, empathy, and physician resource utilization. **Journal of general internal medicine 6:** 420–423, 1991

71.Palese A, Skrap M, Fachin M, Visioli S, Zannini L: The experience of patients undergoing awake craniotomy: in the patients' own words: a qualitative study. **Cancer nursing 31(2):** 166-172, 2008

72. Petersen S, Heesacker M, DeWitt Marsh R: Medical decision making among cancer patients. **Journal of counselling psychology 48(2):** 239-244, 2001

73. Roter DL, Hall JA, Katz NR: Relations between physicians' behaviors and analogue patients' satisfaction, recall, and impressions. **Medical care 25**: 437-51, 1987

74. Sarang A, Dinsmore J: Anaesthesia for awake craniotomy – evolution of a technique that facilitates awake neurological testing. **British journal of anaesthesia 90(2):** 161-165, 2003

75. Shapiro J: How do physicians teach empathy in the primary care setting? **Academic medicine 77**: 323–328, 2002

76. Serletis D, Bernstein M: Prospective study of awake craniotomy used routinely and non selectively for supratentorial tumors. **Journal of neurosurgery 10:** 1-6, 2007

77. Smith JA: Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. **Psychology & health 11:** 261-271, 1996

78. Smith JA, Flowers P, Larkin M: **Interpretative phenomenological analysis: theory, method and research.** London, England: Sage Publications, 2009

79. Spijker A, Trijsburg RW, Duivenvoorden HJ: Psychological sequelae of cancer diagnosis: A meta-analytic review of 58 studies after 1980. **Psychosomatic medicine 59(3):** 280–293, 1997

80. Tarakeshwar N, Vanderwerker LC, Paulk E, Pearce MJ, Kasl SV, Preigerson H G: Religious coping is associated with the quality of life of patients with advanced cancer. **Journal of palliative medicine 9(3):** 646-657, 2006

81. Taylor M, Bernstein M: Awake craniotomy with brain mapping as the routine surgical approach to treating patients with supratentorial intraaxial tumors: a prospective trial of 200 cases. **Journal of neurosurgery 90:** 35–41, 1999

82. The National Collaborating Centre for Chronic Conditions: **Parkinson's disease.** London, England: Royal College of Physicians, 2006

83. Thompson RJ, Gustafson KE, Hamlett KW, Spock A: Stress, coping, and family functioning in the psychological adjustment of mothers of children and adolescents with Cystic-Fibrosis. **Journal of paediatric psychology 1:** 573-585, 1992

84. Thune-Boyle IC, Stygall JA, Keshtqar MR, Newman SP: Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. **Social sciences and medicine 63(1):** 151-164, 2006

85. Tonn JC: Awake craniotomy for monitoring language function: benefits and limits. **Acta neurochirurgica (Wien) 149:** 1197-1198, 2007

86. Tuncay T, Musabek I, Gok DE, Kutlu M: The relationship between anxiety, coping strategies and characteristics of patients with diabetes. **Health and quality of life outcomes 6(79):** 1-9, 2008

87. Vega-Basulto SD: The interview with the relatives of the neurosurgical patient. **Neurocirugia 15(4):**391-398, 2004

88. Vitaliano PP, DeWolfe DJ, Maiuro RD, Russo J, Katon W: Appraised changeability of a stressor as a modifier of the relationship between coping and depression: A test of the hypothesis of fit. **Journal of personality and social psychology 59:** 582–592, 1990

89. Weitzner M, Meyers C: Cognitive functioning and quality of life in malignant glioma patients: a review of the literature. **Psycho-oncology 6:**169-177, 1997

90. Whittle IR, Midley S, Georges, H, Pringle AM, Taylor, R: Patient perceptions of "awake" brain tumour surgery. **Acta neurochirurgica 147(3):** 275-277, 2005

91. Yardley L: Dilemmas in qualitative health research. **Psychology & health 15(2):** 215-228, 2000

Extended Paper

The extended paper is intended to be an adjunct to the journal paper. This will expand on the introduction and methodology in my journal article, present additional support for the superordinate themes, present two new subthemes and develop the points made in my discussion. Finally a critical reflection of my work will be presented. Throughout the research process my decision making has reflected my epistemological position which is explicitly discussed in the method section. *[See section 3.0]*

1.0 Rationale for journal choice

My journal paper was written for submission to the Journal of Neurosurgery. This journal is aimed at neurosurgeons and has an impact factor of 2.769 (Institute for scientific information, 1996). As my study aimed to inform neurosurgeons and their teams about the patients' experience of awake craniotomy I felt that this journal would reach the intended audience. Furthermore, the most recent qualitative publication exploring the patient experience of awake craniotomy (Khu et al. 2009) was published in the same journal. Publishing in the same journal was thought to emphasise the importance of the awake craniotomy and make similar research easily accessible. *[See section 5.6 for critical reflection on how my research fits in with the larger body of scientific discourse]*

The Journal of Neurosurgery author's instructions prohibited the use of a first person account and APA referencing style. Throughout the extended paper I will revert to first person and APA referencing styles.

(Guidance for authors can be found at: http://jns.msubmit.net/cgi-bin/main.plex?form_type=display_auth_instructions*)*

2.0 Extended Introduction

Systematic searches of the literature were conducted to gain an understanding of the evidence base. To do this, major databases were searched, such as PsycInfo, PubMed and MEDline. Terms such as *awake craniotomy, patient perception, patient experience and brain tumour* were utilised.

2.1 The brain tumour

2.1.1 Brain tumour definition.

A brain tumour is an abnormal growth of cells inside the skull or within the brain which multiply uncontrollably (Rose, 2004). Traditionally brain tumours are classified as either benign (non-cancerous) or malignant (cancerous) (Rose, 2004). NICE guidelines (2006) caution against this clinical split due to the possible perception of benign brain tumours as harmless. Therefore, the terms low grade and high grade, referring to grading used by the World Health Organisation (2004), will be utilised respectively. A low grade tumour grows at a slow pace, and does not spread across the body (Marsh, 2005). This kind of tumour could have existed for a long time prior to the onset of symptoms (NICE, 2006). In contrast a high grade tumour is aggressive and infiltrates other regions of the brain and body (NICE, 2006). Either form of tumour can have life threatening implications on the patient and tumours initially diagnosed as low grade are at risk of transforming to high grade tumours (NICE, 2006).

Implications for patient health are caused through tumours placing pressure on the brain, or preventing areas of the brain from functioning correctly. This can cause damage and neurological impairment (NICE, 2006). There is no generic brain tumour diagnosis for patients to undergo awake craniotomy. However the tumour is often intrinsic: a tumour originating from neural and supporting tissue. In addition, the tumour is usually in an eloquent area, or an area of the brain which is associated with important functions, for example movement, sensation, speech or vision. The most common cause for neurosurgery is the understanding that without resection a low grade tumour may transform into a high grade tumour S. Basu (personal communication, October 5, 2010). This is thought to happen in 80% of tumour cases (Bigner, McLendon & Bruner, 1998).

2.1.2 Brain tumour incidence.

The incidence rate of brain tumours report the frequency of which they occur. Of the 6500 new brain tumour cases each year, NICE guidelines (2006) reported that more than half were high grade. However, research suggests that low grade tumours are often under reported (Pobereskin & Chadduck, 2000). Quinn, Babb, Brock, Kirby and Jones (2001) go so far as to suggest that almost half of the brain tumours experienced in England and Wales are not registered.

Of those tumours that are reported, the incidence is increasing. Over a decade, 1991 to 2000, registration of brain tumours had an estimated increase of 17%, (NICE, 2006). Within the general population aged 75 to 79 years the increase was 50% (NICE, 2006). This increase could be due to more accurate diagnosis as well as an ageing population (Davis, Kupelian, Freels, McCarthy & Surawicz, 2001; Jukich, McCarthy, Surawicz, Freels & Davis, 2001).

2.1.3 Brain tumour prevalence.

Prevalence refers to the relative magnitude of two quantities, in this case the amount of people per 100,000 who have a brain tumour diagnosis at any one time. NICE (2006) estimates that 8.54 people per 100,000 have a high grade brain tumour and 1.25 people per 100,000 have a low grade brain tumour. Caution should be taken with these figures as the estimates have been reported to vary from seven to 21 people per 100,000 (Ogungbo, Najim, Mendolow & Crawford, 2002).

2.1.4 Brain tumour survival rates.

Prognosis for brain tumour patients, particularly with high grade brain tumours, is poor (NICE, 2006). Estimated survival rates can be found in Table 3.

Table 3

High Grade Brain Tumour Survival Rates (Adapted from Nice, 2006, p. 15)

	Patients diagnosed 1991-1995		Patients diagnosed 1996-1999	
	1 year*	5 year*	1 year*	5 year*
Men	30.8**	13**	32.2**	12.5**
Women	32.2**	15.4**	32.1**	15.3**

Note. *post diagnosis, **percentage of survival

2.2 Treatment options

2.2.1 Treatment for brain tumours.

Brain tumour treatment can range from surgery, to chemotherapy or radiotherapy depending on the type and position of the brain tumour (NICE, 2006). One type of surgical procedure is known as a craniotomy. The craniotomy can be conducted asleep or awake (Lanier, 2001). There are reported advantages and disadvantages to each option. These will now be discussed.

2.2.2 Craniotomy under general anaesthetic.

Traditionally a craniotomy involves the patient being placed under general anaesthetic. The aim of this is to re-sect the brain tumour and its marginal tissue in its entirety. The benefits of removing the entire tumour include lessening tumour reoccurrence (Lanier, 2001) reducing the probability that the tumour will reform (Sarang & Dinsmore, 2003) and potentially enhancing long term survival (Lanier, 2001; Meyer et al. 2001). However, removing a tumour in this way can potentially have devastating effects on patient function, for example causing paralysis. Given the poor prognosis of brain tumour patients, this is not a desirable outcome for patient or surgeon (Lanier, 2001; NICE, 2006).

2.2.3 Awake craniotomy.

Awake craniotomy has been performed for over seventy years universally (Whittle, Midgley, Georges, Pringle & Taylor, 2005). Over the last decade the use of awake craniotomy has increased and it is now thought to be preferential to traditional brain tumour surgery under general anaesthetic (Meyer et al. 2001; Moritz-Gasser & Duffau, 2010). This is potentially due to its' demonstrated ability to preserve patient function.

The awake craniotomy aims to safely remove as much of the brain tumour as possible. To achieve this aim the patient remains awake to assist the neurosurgeon in "locating the interface between the tumor and functionally eloquent brain" (Lanier, 2001, p. 670). This is thought to help patients function optimally and preserve or improve their quality of life, whist increasing chances of survival (Grant & Metcalfe, 2004; Lanier, 2001; NICE, 2006). Single site studies have reported that when undergoing awake craniotomy less than 10% of patients are left with permanent language impairment (Tonn, 2007) and less than 25% with a long term lifestyle altering functional deficit (Costello & Cormac, 2004; Lanier, 2001). However these figures are not reported against traditional craniotomy data. Although this appears promising preservation of function is not a certainty (Whittle, 2004). Given that awake craniotomy only aims to re-sect part of the tumour, the patient may be at an increased risk of the tumour reforming (Lanier, 2001).

2.3 Quality of life for brain tumour patients.

Quality of life for brain tumour patients is an under-investigated area (Fox & Lantz, 1998; Gilbert, Armstrong, Meyers, 2000). Given that the aim of awake craniotomy is to preserve patient function and the decision regarding the type of treatment is thought to rest on the "desires and life view" (Lanier, 2001, p. 670) of the patient, the effect of treatment choice on quality of life will be discussed.

Literature reports a poorer quality of life for brain tumour patients than healthy controls (Glaus, Crow & Hammond, 1996; Klein et al. 2001; Pelletier, Verhoef, Khatri & Hagen, 2002; Reijneveld, Sitskoorn, Klein, Nuyen & Taphoorn, 2001; Weitzner & Meyers, 1997). This is attributed to the physical, cognitive and

psychological factors associated with a brain tumour diagnosis. Osoba, Brada, Prados and Yung (2000) discussed a comprehensive list of the most common symptoms or impairments suffered by brain tumour patients. Of all of the symptoms fatigue is most often reported (Glaus et al. 1996). However pressure from the tumour on the brain can cause headaches, sickness or visual problems. In severe cases this can extend to fluctuating consciousness and lethargy (NICE, 2006) and the focal deficits experienced by patients can lead to motor weakness or sensory loss as well as speech or comprehension problems (NICE, 2006).

Awake craniotomy cannot help patients to come to terms with a potentially life threatening illness (Heimans & Taphoorn, 2002) or cope with the effect of their diagnosis and symptoms on their loved ones (Wideheim, Edvardsson, Pahlson & Ahlstrom, 2002). However it has the potential to facilitate patients to extinguish brain tumour symptoms and sustain or improve their quality of life (Moritz-Gasser & Daffau, 2010; Weitzner & Meyers, 1997). Research by Weitzner and Meyers (1997) attributed this to awake craniotomy allowing patients to continue with desirable activities through the preservation of function. This could also lead to a decrease in emotional burden (Bradley et al. 2007) as by having the awake craniotomy patients may not suffer many of the psychosocial effects reported in brain tumour research (Armstrong, 2004; Bradley et al. 2007; Cassileth, Lusk, Miller, Brown, & Miller, 1985; Khalili, 2007). For example cancer costs to families can become very high (Bradley et al. 2007) and only 18% of patients with a high grade tumour are thought to be capable of returning to work (Armstrong, 2004).

2.4 Patient experience of awake craniotomy

There is a paucity of literature available on the patient experience of awake craniotomy. The available literature will be reviewed here with particular attention paid to the methodological constraints of the studies.

Three studies have concluded awake craniotomy has good patient satisfaction and tolerance although each study is methodologically flawed (Danks, Aglio, Gugino & Black, 2000; Sarang & Dinsmore, 2003; Tonn, 2007). Danks et al. (2000) reported good patient satisfaction with the awake craniotomy, Sarang

and Dinsmore (2003) reported that patients accepted the awake craniotomy procedure and Tonn (2007) reported that 120 of 150 patients found the awake craniotomy procedure 'not onerous' (p. 1197). However, in each study, no attempt was made to describe the methodology of attaining participants' accounts.

Danks, Rogers, Aglio, Gugino and Black (1998) was the first study to make a more complex attempt at understanding the subjective experience of awake craniotomy. Danks et al. (1998) reported that at least 12 out of 20 patients were completely satisfied with the awake craniotomy. Of the eight remaining the authors reported that three had moderate pain and five had moderate to severe pain. To ascertain these results Danks et al. (1998) utilised a mixed methods design. Methods included a questionnaire, the profile of mood states (Cella et al. 1987) and a structured interview.

The questionnaire and profile of mood states (Cella et al. 1987) were administered by a member of the neurosurgery team. In addition participants were made aware that each method of data collection focused on the problems associated with awake craniotomy, for example the interview focused on signs of post-traumatic stress. It is anticipated that using a member of the neurosurgical team to collect participant data and making participants aware of the aim to identify potential problems may have led to bias in the data obtained. Thus participants may have been guided to discuss the negative aspects of the procedure or may have been more inclined to emphasise problems with the procedure, moving awake from the subjective experience of the participant (Rosenthal & Rosnow, 1969).

Following Danks et al. (1998), Whittle et al. (2005) attempted to address patient perceptions of awake craniotomy through a dedicated questionnaire. Whittle et al. (2005) reported that most participants tolerated the awake craniotomy procedure well. However in this conclusion, Whittle et al. (2005) failed to address the findings that 15-29% of their participants, as reported in the results, found the awake craniotomy uncomfortable, fearful or anxiety provoking. This calls into question the transparency of the data reported (Baxter & Eyles, 1997). In addition the way in which data was obtained was not specified by the

authors, for example if the participants were given a questionnaire to fill out alone or with a member of the neurosurgical team. In either case several factors may have influenced the reporting of data by participants.

Manninen, Balki, Lukitto & Bernstein (2006) reported that 93% of participants were completely satisfied with their awake craniotomy experience, with a particular focus on the anaesthetic management technique. Improving on Danks et al. (1998) the study used an investigator, unknown to participants, to interview 50 participants at three time points following awake craniotomy. Participants were initially asked to recall their experience however this led to more specific questions about particular parts of the procedure, for example the times at which pins were inserted into the skull. All data obtained from participants was than ranked and quantified according to a mild, moderate and severe scale, depending on how many times participants mentioned distressing events. Given the aim, to determine patient satisfaction, little time was given to the participants to express their own views without guided questions. In addition, quantifying interview data could have implications on the reliability of the study, for example there was a potential for researcher bias and implications on the transparency of the data obtained.

The most recent attempt to determine the patient experience of awake craniotomy was through the utilisation of a structured interview. Goebel, Nabavi, Schubert and Mehdorn (2010) reported that satisfaction with the awake craniotomy was high in 24 out of 25 participants. However similarly to Whittle et al. (2005) authors failed to address the 39% of participants, reported in the results, who described minor to moderate difficulties. Goebel et al. (2010) utilised a similar methodology to Danks et al. (1998) however strength of the study was that structured interviews were completed by a clinician external to the neurosurgical team.

In summary, all of the literature attempting to adhere to a more positivist framework has constrained the understanding of awake craniotomy. This is not only through poor methodological considerations but also through a desire to reduce patient perceptions or experiences to statistical analyses. Reasons for the dismissal of qualitative data generated by the studies have not been given.

However, reporting quotes to emphasise statistical results which are later concluded as not significant, leads to the questioning of the transparency of the data and subsequently the reliability of the data obtained.

2.4.1. Qualitative studies.

In contrast to the previous research described, two recent studies, conducted in Canada (Khu et al. 2009) and Italy (Palese, Skrap, Fachini, Visioli & Zannini, 2008) have facilitated patients to express their account of the awake craniotomy experience through the utilisation of qualitative methodology. Given the variation in the countries where the awake craniotomy procedures took place there may be differences in the procedure. Manninen et al. (2005) reported that in Toronto, Canada patients were kept awake throughout the entire procedure. However in the UK, patients are woken following craniotomy, when the brain tumour excision begins. This may impose limits on the ability to transfer the data generated. However cross-cultural research can still add depth to the literature and inform neurosurgery departments about the experience of awake craniotomy.

The qualitative studies have utilised semi-structured interviews prior to and post awake craniotomy. When considering the interview schedules, Palese et al. (2009) encouraged free speech through the provision of a brief interview schedule. However the interview schedule used by Khu et al. (2009) was more extensive and limited the participants' description of the experience through directed questions. It is arguable that this prompted the participants to consider aspects of the experience that may not have been crucial to their experience. However ironically, it was Palese et al. (2008) who reported a more anxiety provoking experience and Khu et al. (2009) who reported a satisfying experience for participants.

In addition to the critique of the schedule itself, both studies (Khu et al. 2009; Palese et al. 2008) conducted two interviews, prior to and post awake craniotomy. This may have generated a superficial split in the participants' experience of awake craniotomy, and forged a purposeful focus on the awake craniotomy procedure itself. Despite this split Khu et al. (2009) discussed the low priority of the awake craniotomy procedure, in contrast to alternative parts

of the experience. It is arguable that conducting a single interview, following the entire awake craniotomy experience, would shed light on the participants experience and the importance they place on individual aspects of awake craniotomy.

An additional point of critique for Palese et al. (2009) was the sample size. The authors interviewed 21 participants on two occasions. Consequently the depth of the analysis could be questioned. This may be representative of the analysis completed. Palese et al. (2008) conducted phenomenological analysis. This has been reported as constrained by its lack of interpretation or integration on part of the researcher (Finlay, 2009). *[See 3.1.4 for further discussion on alternative approaches to analysis]*

Method

The following section develops the methods section in the journal paper. This will provide a comprehensive overview of the methodology, including rationale for qualitative research and interpretative phenomenological analysis (IPA; Smith, 1996), as well as a discussion on the epistemological position of the researcher.

3.1 Study rationale

3.1.1 Researcher characteristics and epistemological position.

I am a trainee clinical psychologist whose work is informed by systemic, cognitive-behavioural, psychodynamic and attachment perspectives. I have an academic and clinical interest in applied neuropsychology, demonstrated through previous research within this arena. Prior to commencing the current research I have had no research experience using qualitative methodology. I was drawn to qualitative research, and specifically IPA, as previously I have felt constrained by the limitations of the interpretative framework in quantitative methodologies.

Conclusions made in my previous research have focused on statistical analyses. I can appreciate the utility of quantitative research, for example its ability to generalise across populations. However I do not adhere to a quantitative paradigm in my clinical work, particularly when developing formulations. As a trainee clinical psychologist my work is grounded in the central tenets of a critical realist epistemological position (Bhaskar, 1975). Thus, I accept that past experiences influence how we behave and what we say, irrespective of attempts to "bracket" (Kvale, 1996, p.54) these experiences.

In relation to the current study, a critical realist position proposes that participants and researchers can experience objective events in different ways depending on individual "thoughts, beliefs, expectations and judgments" (Willig, 2008, p. 70). This means that my access to the participant's experience is dependent not only on what the participant discloses (Smith, Flowers and Larkin, 2009) but also on my own personal life experiences (Bhaskar, 1975). Although I have no personal experience of brain tumours or awake craniotomy,

I accept that my experiences and personality may influence my view of awake craniotomy. This may have influenced my choice to complete this study in the first instant, as well as the data collection, analysis and write up conducted. An example of this is my consideration of conducting qualitative research with the aim of publishing in a medical journal. This plays a small role in facilitating the move towards qualitative research being respected in healthcare (Brocki & Wearden, 2006), as well as in evidence based medicine (Popay & Williams, 1998). I felt being part of this movement was important as this is consistent with my beliefs as a trainee clinical psychologist.

3.1.2 Rationale for qualitative methodology.

The aim of the current study is to explore the patient experience of awake craniotomy. Given the paucity in research, I wanted to utilise a methodology which would move the literature towards a greater understanding of the awake craniotomy, thus a method which was appropriate to what I was trying to find out (Punch, 2005; Turpin et al. 1997). Previous research exploring patient experience of awake craniotomy (e.g. Danks et al. 1998; Manninen et al. 2006) has illustrated a tendency to use structured interviews, containing the exploration of experience through adhering to an unrealistic objectivity (Hammersley, 2000). In particular, Whittle et al. (2005) illustrated the priority of some research to develop technology, such as a questionnaire, to reduce observable qualities to statistical analyses (Yates & Yates, 2004). Understanding the subjective experiences of awake craniotomy is essential, therefore quantitative methodology was felt to be inconsistent with the aim of the current research, to explore the patient experience through the "meaning, interpretation and understanding" (Turpin et al. 1997, p. 4) offered by the participant.

Not wanting to adhere to an unrealistic objectivity is also appropriate to my second rationale for qualitative research. When aiming to explore the patient experience of awake craniotomy, the potential that I would only have access to a small sample size was taken in to consideration. Given the rare nature of brain tumours and the infrequent practice of awake craniotomy in the United

Kingdom, I anticipated that recruiting participants may face difficulties. For this reason, quantitative research, or research aiming to generalise findings, was felt to be inappropriate and unfeasible for the current study.

To summarise, qualitative methodology is consistent with my research aim, it is a feasible option and it can accommodate my critical realist epistemological position. Furthermore it fits with my position as a researcher as I wanted to diversify from my quantitative background in an attempt to widen my knowledge base. Exploring the patient experience of awake craniotomy has given me this opportunity whilst allowing my research to continue in the neuropsychological arena.

3.1.3 Rationale for IPA.

IPA emerged in the later part of the 1990's, advocated by Smith (1996). A reason for choosing IPA analysis for the current study was based on its multi-faceted approach. The combination of phenomenology and interpretation (Smith et al. 2009) matched the aim of my study and was consistent with my critical realist epistemological position.

Phenomenology.

Phenomenology is concerned with exploring an experience in its own terms (Husserl, 1970). Finlay (2009) reported that IPA deviates from traditional Husserlian phenomenology and instead is phenomenological in "its concern for individuals' perceptions" (Finlay, 2009, p. 2). Thus the aim of the phenomenological aspect of IPA is to bring the meaning to the centre of the analysis, whilst trying to understand the substance and complexity of the meaning (Smith & Osborn, 2008). This involves exploring how people make sense of and perceive specific life experiences (Smith et al. 2009), and is achieved through asking critical questions of the data, gaining an understanding of what lies underneath what the participant is saying (Smith & Osborn, 2008).

Exploring a specific experience using IPA fits with the current study as the aim is to explore patients' experiences of awake craniotomy. In this respect I am attempting to understand the time where participants are momentarily aware of their experience of awake craniotomy, rather than immersed in the everyday flow of life (Smith et al. 2009). Further support for the use of IPA in the current study comes from comparisons with previous IPA studies. The topic of the current study is synonymous with previous IPA research exploring health conditions (Smith, 1996), novel experiences (Smith, Michie, Stephenson & Quarrell, 2002) and life-threatening events (Smith, 2004).

Hermeneutics.

Understanding the phenomenological aspects of IPA is only a starting point. To understand IPA in its entirety the hermeneutic tradition, or interpretation, must also be considered. As discussed IPA accepts that the researcher plays an active role in understanding the participants' interpretation of their experience (Smith et al. 2009). In this respect IPA accepts that researchers' engage in a double hermeneutic process, thus the analysis itself is the researchers' interpretation of the participants' interpretation of their experience (Bhaskar, 1975; Smith et al. 2009). In addition IPA does not support the use of bracketing (Smith, 2004). Therefore in its entirety IPA is synonymous with a critical realist position as it is suggesting that analysis can and should make inferences about peoples' experiences, and that researchers will inevitably play a role in the data analysis.

The double hermeneutic in IPA fits with the current study due to the acceptance that previous knowledge and experience will influence both participants and the researcher. The participants will be influenced in their speech and choice of language and the researcher in their analysis and interpretations. This is particularly poignant when considering the empathy I share with the data and my questioning of it (Smith et al. 2009). As a trainee clinical psychologist I am accustomed to being inquisitive of both behaviour and discourse. IPA supports this inquisitive nature through the double hermeneutic (Smith et al. 2009), allowing me to know the data through my own experiences.

In addition the use of IPA fits with the current study due to the population of awake craniotomy patients available to take part in research in the United Kingdom. This is consistent with IPA (Smith et al. 2009) which proposes that a sample size of between four and ten is adequate to allow space for "time, reflection and dialogue" to a high level (Smith et al. 2009, p. 42).

3.1.4 Critique of IPA and alternative approaches.

Each method of qualitative analysis applies a different theoretical interest to the analysis of the data. As discussed, the two existing studies exploring patient experience of awake craniotomy have utilised thematic analysis (Khu et al. 2009) and phenomenological analysis (Palese et al. 2008). These will be considered whilst developing a critique of IPA. *[See section 2.4.1 for further discussion on methodological shortcomings of these studies]*

Thematic analysis.

Thematic analysis aims to extract patterns or themes from participant data (Braun & Clarke, 2006). It has been described as a generic approach to data analysis and recommended as the first method which should be learnt by a new researcher as it offers a flexible approach to data analysis (Braun & Clarke, 2006). Advocates of thematic analysis praise its independence from theory or epistemology, claiming this can yield rich and complex accounts (Braun & Clarke, 2006). This was apparent in the awake craniotomy study by Khu et al. (2009). However more positivist thematic analysis can be consistent with traditional quantitative paradigms and therefore only offer a descriptive account of the data.

The current study is arguably more suited to the theoretical ties of IPA (Smith, 1996). The emphasis on the hermeneutic would secure an in-depth and complex account of the experience. It is recognised however that as I am a first-time researcher, this was at risk of loosely adhering to a cookbook method of which IPA has received criticism (Braun & Clarke, 2006).

Phenomenological analysis.

Phenomenological analysis is somewhat different to the phenomenological aspect of IPA (Finlay, 2009). The aim of phenomenological analysis is to reduce lived experiences to their embodied or experiential meaning (Wertz, 2005). The advantage of adopting a phenomenological perspective is that it can be highly revealing regarding the experience (Finlay, 2009). However, it has faced criticism for lacking an interconnection between the researcher and the data as it requires the researcher to bracket previous experiences and knowledge (Finlay, 2009). In this respect Phenomenological analysis is inconsistent with my epistemological position.

Due to my epistemological position the current study is more suited to the explicit incorporation of the hermeneutic in IPA (Smith et al. 2009). In addition IPA is thought to have more impact at a scientific level and is increasingly accepted in healthcare research (Brocki & Wearden, 2006; Popay & Williams, 1998).

Critique.

Each methodology has strengths and weaknesses. In respect to IPA several factors can be taken in to consideration. IPA, and most other qualitative methodologies take a backwards focus on a participants experience, gathering retrospective descriptions of an account (Smith et al. 2009). This can arouse issues of perceptual error or deceit from the participant (Giorgi & Giorgi, 2008). Participant deceit in IPA studies may not be purposeful but could unconsciously move the researcher towards a certain way of thinking about the experience. For example, a participant who has a successful awake craniotomy procedure may want to display gratitude to the neurosurgery team. This can be overcome in IPA due to the longer, semi-structured interviews, which should allow space and time for honest accounts to present themselves (Giorgi & Giorgi, 2008).

The honesty of IPA, the declaration that it is a subjective methodology, can overcome this aspect, as there is no intention to deceive outsiders that the analysis is based on objective reports. In addition IPA's interest in the situation or phenomenology extends to the way in which participants discuss their experience, thus the factors which stand out about the experience to individual participants can be revealing (Giorgi & Giorgi, 2008).

3.1.5 Summary.

All qualitative methodologies admit to the interpretative element of the researcher throughout the research process (Elliot, Fischer & Rennie, 1999). However the focus of IPA on a specific experience, linked with the acceptance of the inherent interpretation by the participant and the researcher confirmed my decision (Smith & Osborn, 2008). Thus, IPA is consistent with my research aim, my research focus: awake craniotomy and my epistemological position. This decision was further reassured through the labelling of IPA as the "method of choice" in healthcare research (Biggerstaff, 2008, p. 214).

3.2 Participants

3.2.1 Purposive sampling.

Purposive sampling is the selection of participants to represent certain subject characteristics relevant to the research study (Stommel & Wills, 2004). In the current study that is patients who have had an awake craniotomy procedure. This is supported by the phenomenological aspect in IPA, thus an attempt to explore participants' perception of a specific experience (Smith et al. 2009). In adhering to purposive sampling I was not aiming to generate a sample that was representative of a more expansive target population (Stommel & Wills, 2004).

3.2.2 Homogeneity.

The aim of IPA is to recruit a homogenous sample (Smith et al. 2009). A homogenous sample helps to establish the rigour of the study (Yardley, 2000).

This is through the sample allowing the analysis of convergence and divergence in detail. In aiming for a homogenous sample any immediate claims are constrained by the group studied and thus their experience of the experience in question. However the researcher can use professional knowledge to assess the evidence and consider its theoretical generalisability (Smith et al. 2009).

3.2.3 Participant withdrawal

As discussed, one participant became distressed during an interview. I managed the participant's distress using my clinical skills and reminded them of their ethical rights to discontinue participation. At this point the participant withdrew from the study. Prior to leaving their home I directed the participant to the contact numbers on the information sheet. In addition I reinforced that should they need extra support that they should contact his G.P. *[See 3.7 for further discussion on ethical considerations and 5.6.2 for critical reflection on the participant withdrawal from the study]*

3.3 Participant recruitment

3.3.1 Procedure.

The procedure followed steps outlined by Smith et al. (2009) for researchers conducting an IPA study. Throughout the study I was mindful of using a step-by-step method as this is not consistent with a critical realist position. However, this method is thought to be most useful for first-time IPA researchers (Smith et al. 2009). As I was new to IPA, I decided that following this structure and reflecting on it in light of pre-existing scholarly knowledge would be sufficient to satisfy the epistemological position and not buy into a prescriptive method (Smith, 2004).

Participant recruitment commenced following single site ethical approval (appendix E) and research and development approval (appendix F) in November 2009 and January 2010 respectively. The study was given favourable opinion with few amendments. Amendments included a request to see the interview schedule and minor changes to the participant information sheet (for full details see appendix G).

Patient eligibility was determined through information held at the Department of Neurosurgery and through liaison with participants. Participants opted into the study following receiving an information pack (see appendix A, B & C) from the Department of Neurosurgery on my behalf (see figure 2 for recruitment flow chart). Asking the department to send out information packs allowed patients to remain anonymous until they made the decision to opt-in to the study. Recruitment methods were agreed with the Consultant Neurosurgeon at the Department of Neurosurgery who completed checks to ensure deceased patients would not receive an information pack.

3.3.2 Information packs.

The information pack received by participants contained a cover letter, an information sheet, an opt-in slip and a stamped addressed envelope (for cover letter, information sheet and opt-in slip see appendix A, B & C). Patients were asked to opt-in to the study by contacting me using the opt-in slip, telephone or email. Due to the small number of potential participants available, potential participants who had not opted-in to the study following a two-week period were re-approached with a follow-up information pack (for follow-up letter see appendix H). No further contact was made with the participant if they did not opt-in at this point. On receiving a participant's wish to opt-in to the study I allowed time to discuss any questions by email or over the telephone, and subsequently a time and location was arranged for the interview to take place.
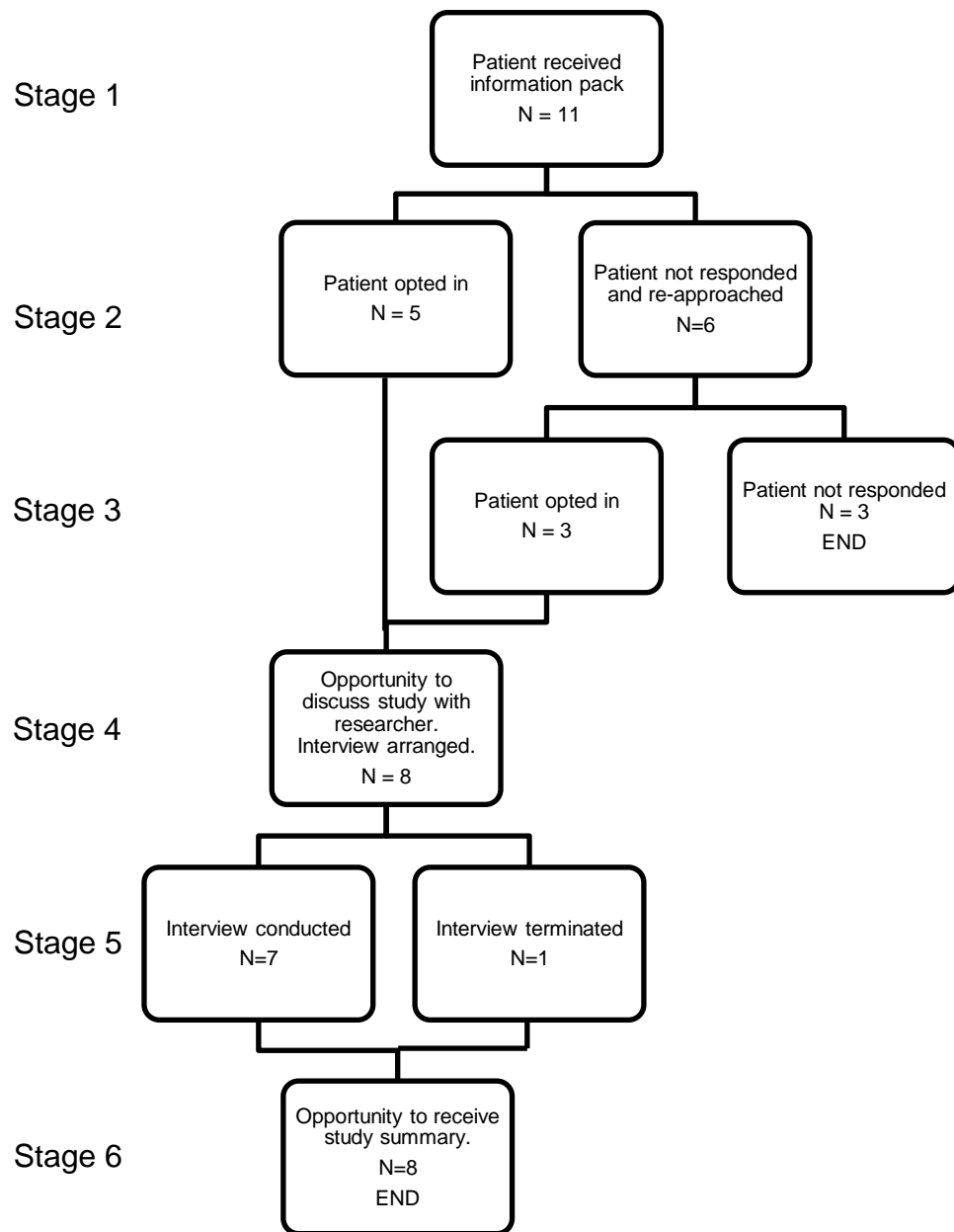
Figure 2. Recruitment flow-chart

3.4 Data collection

3.4.1 Interviews.

Following recruitment I conducted and audio-recorded eight semi-structured interviews. As discussed, one interview was terminated and the data withdrawn from the analysis. Using IPA methodology limits the data collection methods available to me as a researcher. Proponents of IPA advocate face-to-face, semi-structured interviews (Smith et al., 2009) which have been used in the majority of IPA studies (Brocki & Wearden, 2006). More recently IPA studies have also used focus groups (Flowers, Duncan & Frankis, 2000). In line with my epistemological position I decided that a semi-structured interview would give me the most insight in to the participant's experience and allow them to report their experience openly. Through following the interview schedule and chasing down the experiences discussed this gave the experience the maximum potential to present itself (Larkin, Watts and Clifton, 2006).

Participants had the option to travel to the University of Nottingham and receive travel expenses if they preferred. However, it was advised that home visits would facilitate comfort and privacy. On three occasions a partner was present at the request of the participant. Prior to commencing the interview I explained the purpose to the participant and they were given the opportunity to ask any questions. At this point it was made clear that the partner's input should be minimal. This was to ensure that a third hermeneutic was not added to the interview. Thus if the partner of the participant had commented during the interview it would be my interpretation, of the partner's interpretation of the participants interpretation of the experience. Participants were then asked to read and sign a consent form (see appendix I) and complete a brief demographic questionnaire (see appendix D). Minimal information was required due to the exploratory rather than comparative nature of the study. *[See section 3.7.2 for further discussion on gaining informed consent]*

Finally the participant was thanked for their time and offered the opportunity to receive a study summary following thesis write-up (for study summary request form see appendix J). Each participant was left with contact details of the

clinical supervisor, advice to contact their general practitioner if any issues arose and the contact details for the Patient Advice and Liaison Service (PALS). Participants were also given the opportunity to ask any questions and reminded that they could withdraw from the study up to 48 hours following the interview. Participants had my contact information and the chief investigator's if they wanted to make contact.

Each interview was then transcribed verbatim following a 48 hour withdrawal period. External transcription was considered but ruled out. Although this would have been an economical solution, in terms of time, the cost of external transcription was substantial and may have exceeded the budget available to me to complete the doctoral research. Furthermore, IPA methodology emphasises the importance of data engagement through transcription, allowing for a more thorough analysis process (Smith et al. 2009).

3.4.2 Development of the semi-structured interview schedule.
[For interview schedule see Table 1 in journal paper]

To conduct the interview IPA recommends the development of a semi-structured interview schedule. In the current study schedule development followed an iterative process designed by Smith et al. (2009). Initially I consulted existing literature to consider the scope of information accessible when asking how people diagnosed with a brain tumour think about the experience of awake craniotomy. I then held consultations with the academic and clinical supervisors which resulted in the schedule being redrafted and reduced.

The final interview schedule followed a temporal sequence to explore the experience in its entirety. This allowed for scene setting, for example the interview began by taking the participant back to their decision to have the awake craniotomy. This gave the participant time to relax into the interview, or funnel information, prior to discussing the central aspect of awake craniotomy itself. When the interview arrived at the awake craniotomy the participant was asked 'can you tell me about your awake craniotomy?' This open-ended

question encouraged individual interpretations and reflections on the experience in line with IPA methodology and a critical realist epistemological position.

The interview schedule had no formal prompts for the researcher to follow. This was to ensure that the interview loosely followed the schedule but was not directive in its approach. The use of minimal prompts is supported by Smith and Osborn (2003). On completion of schedule development it was piloted with a colleague who was also a trainee clinical psychologist. This process provided information regarding content including the approach to sensitive information and the language used. This is considered an important step in the research process primarily because of the sensitivity of working with cancer patients (McIlfatrick, Sullivan & McKenna, 2006). During the interview the interview schedule was not referred to directly. However, my knowledge of the schedule was sufficient to loosely follow the questions in line with the interests and views offered by the patient.

3.5 Analysis process

The overarching aim of IPA analysis is to make sense of the individual's experience (Smith et al. 2009). To do this IPA is an inductive process, rejecting hypotheses in favour of open-ended research questions. As a first time researcher I endeavoured to adhere to Smith et al. (2009) stages of analysis which are described below. However this was treated as a flexible method of analysis, moving in both directions through the analysis, rather than a cookbook prescription.

Working through the stages of analysis was an iterative process (Smith et al. 2009). Transcripts were worked through sequentially in order to move from the participants account to the joint account and from the descriptive account to the interpretative account (Smith et al. 2009). In doing this I was part of a cyclical process. This involved moving from the individual participant's descriptive account to my own interpretation and back to the individual's descriptive account (Smith et al. 2009).

Throughout each transcript analysis I was mindful of themes emerging from the data. I paid attention to similarities, differences and novelties within the data set. This process was evolving throughout analysis and took place for both individual transcripts and across multiple cases. In doing so I engaged with the individual data and my own psychological knowledge to make interpretations of what the data meant for participants. Whilst completing this process an audit trail was kept to ensure any interpretations could be traced back through the stages of analysis. These stages will now be described in more detail. (See appendix K to follow the stages of analysis with additional reflective diary extracts for one participant, Emma) *[See 3.6.1 for further discussion on the audit trail]*

Stage one: Active engagement.

I transcribed each interview, allowing around eight hours per transcription. Following transcription I familiarised myself with the data. To do this I listened to the audio-recording during reading and re-reading the transcript. The aim of this process was to focus the analysis on the descriptive account of the awake craniotomy experience offered by each participant.

Through reading and re-reading I was also able to move from the chronological account offered by the participant, in line with the interview schedule, and gain a more comprehensive overview of the transcript. I came to know the transcript, including parts where the interaction between myself and the participant was lacking in fluidity and the parts where the interview was richer and in full flow (Smith et al. 2009).

Stage two: Initial noting.

To engage with the data on an exploratory level I carefully examined the participants' transcripts, line-by-line (Larkin et al. 2006). To record the analysis I divided the transcription page in to three columns: transcription, exploratory comments and emergent themes. For the first stage the right hand column, or exploratory comments was utilised. (For extract see appendix K, part A for example).

When conducting the analysis stage two was intertwined with stage one. Thus the process began by noting down anything of interest which arose through transcript reading and re-reading. Although this involved an element of free reading I was guided by levels of analysis presented in Smith et al. (2009): descriptive, linguistic and conceptual reading.

The descriptive comments made had a clear focus on the participants' experience of awake craniotomy. This focused on what mattered to the participants and the meaning they attributed to their experience. In addition analysis noted where the participant led the interview given their freedom of speech (Smith et al. 2009). This helped me to understand the "objects which structure the participant's thoughts and experiences" (Smith et al. 2009, p. 88).

The central focus of the linguistic comments was on the language being used by participants (Smith et al. 2009). This can help to reflect the way participants have presented meaning or context. The focus of my linguistic comments mainly highlighted linguistic features, for example pauses, participants whispering, or raising their voice and sarcasm. Indications were also noted about a participants' hesitancy when discussing a topic. This was felt to be important as it gave clues regarding the nature of a participants' description, for example where a participant struggled to speak about their initial diagnosis. Metaphors and similes were also noted.

The conceptual comments were facilitated by the linguistic and descriptive comments (Smith et al. 2009). This involved taking what the participant was talking about, as well as how they were talking about it. This led to interrogation of the data and abstract thinking, in an attempt to engage in an analytic dialogue. When completing conceptual noting I wrote down questions I was asking myself as I was reading the data. This moved me away from the participants' data towards a coherence of what they were discussing. An example of this is where Emma was talking about keeping herself busy and I was questioning what this would achieve for her prior to the awake craniotomy.

It was at the stage of the conceptual comments where I first became aware of my own personal reflections on the data. A critical realist epistemological position proposes that this is inevitable at some stage. An example of this is

when I thought about times when I have kept myself busy and what purpose this has served for me. This facilitated my engagement with the data and opened my mind to possible meanings or interpretations. The process of noting was complete when the transcript had come to an end.

Stage three: Developing emergent themes.

To develop emergent themes I diverted my attention to capturing an understanding of the presented data. This attempted to reduce the data already derived through identifying "interrelationships, connections and patterns between exploratory notes" (Smith et al. 2009, p. 91).   To do this I began reading through the transcript and exploratory comments together, and used the left hand column, to develop emerging themes (Smith & Osborn, 2008). (For extract see appendix K, part B for example).

As this stage took me a step further away from the data I felt a growing sense of centrality in my role. This was due to the fragmentation across the data. Therefore, whilst the data remained true to the participant account, at stage three I was more inclined to place my interpretations on the data, forming a synergy of the two (Smith et al. 2009). In doing so, exploratory data was transformed in to succinct statements with the aim of capturing the essence of the data. Stage three was complete when the transcript had come to an end.

At this stage I utilised supervision to ensure that he could see the rationality behind my emerging themes. *[See 3.6.2 for further discussion on use of supervision]*

Stage four: Connecting the themes.

When attempting to connect the themes the left hand column, emerging themes, was separated from the data. Thus, to begin I made a chronological list of themes as they appeared in the transcript. To condense the themes, prior to thinking about how they fit together, a frequency chart was developed. (Appendix K, Part C). The frequency did not indicate the importance of the theme rather it was a useful way to conceptualise the themes identified (Smith et al. 2009).

On completion of condensing the themes I began to consider how they might fit together. To do so a level of creativity and innovation was utilised. A combination of abstraction and subsumption dominated the analysis process. The analysis then moved to a theoretical ordering. This involved making sense of the relationships between themes and clustering themes together. Thus as links were identified between emerging themes they were linked together through abstraction: where all the themes gained a representative title, or through subsumption: where one of the emerging themes became the title of a group of themes (Smith et al. 2009). Attention was also paid to contrasts between themes and the contextual factors, for example all participants turning to a family member for support at the point of brain tumour diagnosis.

Once themes were grouped, a table was developed to represent the emergent themes. (Appendix K, Part D). This then evolved in to a larger table incorporating the superordinate theme, subordinate theme, quotes representing the theme and page and line number where it could be located in the data (for extract see Appendix K, Part E). This involved referring back to the raw data to ensure that the themes being interpreted were consistent with the data. In doing so a theme table was developed relating the theme to the data and its place in the transcript noted.

At this point of analysis for each transcript notes and commentaries were made in the reflective diary. This helped to reflect on the decisions made through the different transcripts, and to consider the reason for discarding any themes. *[See 3.6.3 for further discussion on reflective diary]*

Stage four: Moving on.

Each reading has the potential to develop new insights in to the data (Smith & Osborn, 2008). Therefore on completion of one transcript I moved on to the next. When doing this I was aware of the themes from the prior transcript however I allowed new themes to develop given the new data. In this respect I was not endeavouring to reach a saturation of the data as this is inconsistent with the aims of IPA (Smith et al. 2009).

Stage five. Patterns across transcripts.

On completion of each individual transcript I began to look for emerging patterns across the participants. To do this each emergent theme table was laid out and I began a questioning process. This led to the separation of all superordinate themes and a creative process of grouping themes according to their content, their potency and their support for one another. This led to some of the themes being reorganised in line with the new information (Smith et al. 2009).

In addition to this part of the analysis I also identified the recurrent themes for the sample of participants (Appendix M, Part F). I did this due to my sample size of seven participants. Smith et al. (2009) suggests that where samples become larger this is a useful task. Therefore this did not lead my analysis but informed it through presenting themes which were recurrent in more than half of the participants (Smith et al. 2009).

At this stage I utilised supervision from my research supervisor to ensure that he could see the rationality behind my combined themes. Subsequently a diagram representing themes identified was developed (Appendix M, Part G). Analysis then continued in to the write up of the study, this involved creating additional diagrams to comprehend the links between the themes (Appendix M, Part H).

3.6 Quality assurance methods

Conducting IPA is a complex process. In order to assert the validity and quality of the current research, given the inherent subjectivity of the researcher, I have utilised several strategies. These included keeping an audit trail, using supervision and keeping a reflective diary. Each of these will be discussed with reference to trustworthiness (Lincoln & Guba, 1985) and transparency, as well as the quality criteria set out by Yardley (2000).

3.6.1 Audit trail.

Trustworthiness (Lincoln & Guba, 1985) was sought through keeping an audit trail of analytical decision making, detailing any events, influences or actions. This ensured that interpretations made could be traced back through the data (Smith et al. 2009), facilitating the validity of the research. As described and

illustrated in the analysis process *[See 3.5]* the data acquired and the evolving analysis was filed away. This helped to confront record keeping challenges in IPA where intrinsic decisions can be questioned if a rationale is not clearly displayed. This is important from a critical realist perspective as I accepted that my interpretations of the participant data would change depending on the context I was in (Bhaskar, 1975).

Transparency was also shown through a more obvious audit trail, the write up of the thesis (Smith et al. 2009). This is evidenced in the current study, such that there is a clear description of the participants and how they were selected, a description of the interview schedule development and interview process, and the analysis stages worked through (Smith et al. 2009).

3.6.2 Use of supervision.

Supervision was utilised to check the plausibility on my interpretations (Smith et al. 2009). Supervision enabled me to discuss the evolving themes throughout the research process. For example, in the initial stages part of a transcript was taken to supervision and I checked with my supervisor that he could see the emerging themes coming from the data. On the completion of all the transcripts the large theme table was taken to supervision to ensure that my supervisor could 'see' my clustering of themes.

3.6.3 Reflective diary.

The individual researcher's effect on the thesis findings has been proposed as creating the potential for a credibility problem (Madill, Jordan & Shirley, 2000). The reflective diary was utilised to think about the processes I went through and key decisions I made, from data collection to data write up (Smith, Jarman & Osborn, 1999; Smith et al. 2009). The aim of the reflective diary was inform my analysis and allow for transparency (Yardley, 2000)

Although writing in my reflective diary became a continuous process for me I will describe three occasions where I felt this was necessary. First I made notes about my pre-conceptions having spoken to or emailed a participant. This was based on my position that the experience and context of the contact with the participant may, consciously or unconsciously, shape the account that the

participant offers as well as my own approach to the analysis and the subsequent themes identified (Bhaskar, 1975).

Second, I made notes immediately following each interview I conducted (appendix L). These were to account for the critical realist acknowledgement that knowledge is transient. Thus, at a different time and in a different context, the same participant could give a different account of their experience and I could interpret the data differently (Bhaskar, 1975). Therefore, on leaving the interview location, I made reflective notes on the process of the interview, how the person made me feel before, during and after the interview, the judgments I made about the person and my instinctual reaction to their experience.

Third, I made notes throughout my data analysis. These detailed any choices I made regarding theme dismissal, inclusion or exclusion of themes. These helped me to reflect on my rationale and were useful to read prior to supervision sessions (See appendix K).

3.7 Ethical Considerations and seeking ethical approval

Ethical considerations were made throughout study development, data collection, data analysis and write-up. These will now be discussed. *[Ethical approval has also been discussed previously in section 3.3.1]*

3.7.1 Risk of harm.

Prior to study commencement the potential benefits and risks were studied. Potential benefits of taking part were thought to include the possibility of the study validating the experience of the patient and empowering them. The interview could also have a cathartic effect, promoting healing (Hutchinson & Wilson, 1994). The potential drawbacks of the study included the opportunity for the interviews to provoke sensitive and spontaneous conversation, leading to distress. The occurrence of adverse events as a result of participation in the study was not expected, however contingencies were made. I am a trainee clinical psychologist and so could provide a sufficient level of support if distress occurred. The participants were also made fully aware, through the information

sheet, consent form and discussion, that they could take a break or withdraw at any time during the interview. This was emphasised throughout the recruitment and interview process, as discussed when considering the withdrawal of a participant. *[See 3.2.3]*

3.7.2 Informed consent.

The opportunity was given to the patients to discuss the study prior to arranging a time for the interview to take place. This included informing the participants that the research could be submitted for marking by the university and potentially published. It was reinforced to participants that every effort would be made to protect their confidentiality. The opportunity to ask questions was re-emphasised on the day of the interview and prior to the consent taking process. Participants then completed the consent form (appendix I). At this stage I assumed that all patients had capacity to consent as there was no evidence to suggest otherwise (Mental Capacity Act, 2005).

3.7.3 Confidentiality, anonymity and information storage.

Confidentiality was ensured through several methods. Once the interview was completed audio data was transferred to computers at the University of Nottingham and encrypted. During transcription I replaced names and places with pseudonyms to ensure that participant identification was not possible. On completion of transcription the audio data was transferred to individual Compact Discs (CD). This was labelled and deleted from University of Nottingham computers. Demographic information sheets and interview transcripts were also labelled with an interview code. All data was then stored in a locked filing cabinet at the University of Nottingham. Data sheets containing participant information, for example the consent form and study summary request, were stored in a separate locked filing cabinet at the University of Nottingham. A sheet connecting participant data with interview codes was stored in a separate filing cabinet to other data at the University of Nottingham. All data will be stored for a period of seven years at the University of Nottingham in accordance with the code of conduct and to ensure adherence to the Caldecott Principles (DOH, 1997).

4.0 Extended results

This section will elaborate on two of the three superordinate themes: *operation environment* and *information*. In addition two sub-themes: *physical aspect* and *involving the family* will be intertwined. For conceptualisation of where these subthemes sit within the scope of the analysis see figure 3. Although participants discussed each of the additional subthemes it was understood that they were not as important to the participant experience as the themes discussed in the journal paper.
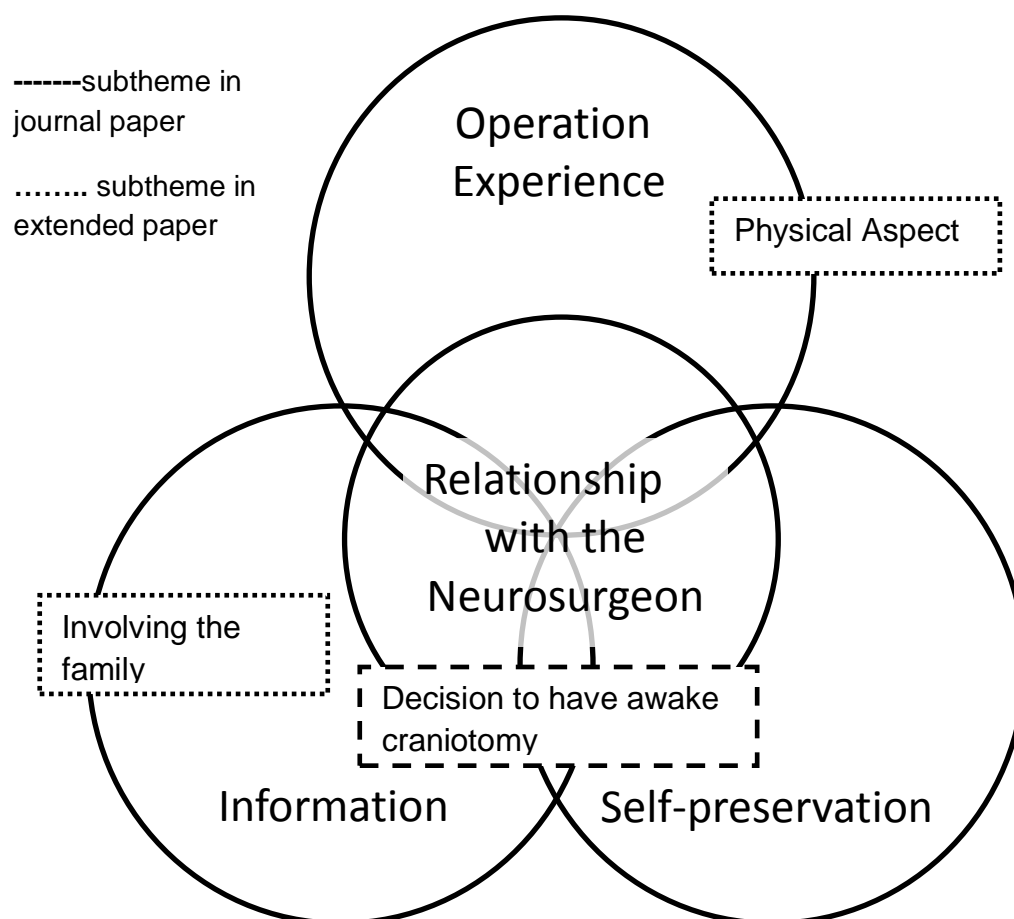
Figure 3: Conceptualisation of all themes identified through the analysis.

4.1 Further quotes, additional thoughts and added subtheme for op*eration environment.*

Due to the contrasting nature of the evidence base for understanding the experience of awake craniotomy it was felt that additional quotes from participants emphasising their experience during the awake craniotomy might be useful. As discussed participants' were reported that the operation felt 'bizarre':

> Sundeep: ...they [surgery team] asked me to move my arm, I couldn't...that felt, really really really [long pause] weird. It felt unbelievably [long pause] it's like...you've got your neuron sending information down to your arm for it to move, and you've just been moving it, and then you can't move it, it's very, what's the word, it's very, I don't know, not having control over your own body, just feels very, don't want to say scared but intimidating... made me feel a bit strange

Despite this they continued to report the positive psychological space in the awake craniotomy:

> *Sundeep*: ...yeh it's just fantastic [laughs] so yeh, it was an experience, an interesting experience, umm one that was equally as enjoyable...but umm surreal at the same time

> Craig: ...umm intrigued more than anything...it was something different, a novelty

> Craig: ...I don't know how to put it into words really, my sort of more inquisitive side, was more prevalent than anything else, I was more intrigued in to what was actually gonna happen rather than sort of worrying about what was happening

It was interpreted that participants may have used their *self-preservation* strategies during the awake craniotomy. For example Emma and Rachel reported joking with the neurosurgeon about his ability to conduct the surgery:

> Emma: ...I said I hope you've got a steady hand [laughs], you weren't drinking last night

> Rachel: ...I said I've just bought my dancing shoes for Christmas do if you leave me in a wheelchair I want a refund [laughs]

Physical aspect.

All participants reported aspects of the physical *operation environment*. However, the small amount of time dedicated to the discussion of these aspects led to my decision that, in contrast to the themes discussed in the journal paper, it was not of primary importance to the participants' experience of awake craniotomy. It was understood that participants did not find the physical *operation environment* anxiety provoking:

> Craig: ... it was an odd one, cos there was no sort of no shock there was no sort of like wow, and there was no sort of like bang to any of it [the awake craniotomy]

> Emma: ...no really comfortable in the operation itself in the theatre when I came round...I say we were all sort of, it wasn't [pause], they made it quite a light sort of experience really, it wasn't sort of [pause], I don't know if anything went sort of went off I was unaware of it

> Emma: ...Lying there with your head open it umm [laughs] I mean I mean I suppose y'know heart surgery and things but umm yeh so yeh so they did make it a good environment for that to happen

Craig emphasised the normality of the awake craniotomy. This was consistent with the reports of other participants:

> Jo: ...and it wasn't painful or uncomfortable and it wasn't frightening and it's definitely the way to go... there was nothing about having it done awake that was in any way horrible

> Emma: ... but umm no it's just y'know just normal really, it just, I didn't sort of feel any pain or anything

The normality associated with the awake craniotomy extended to the awake task that participants were asked to do during the operation:

> Emma: ...well just like normal [referring to the awake task during the awake craniotomy], to be honest it wasn't, I didn't have to, it, think about   it or you know it wasn't any great strain

> Jo: ...during the operation I think I was just quite happy, telling him the answers, I just felt quite happy [laughs]

Emma discussed that it felt quite normal to be completing a task. Similarly Craig reported feeling that his involvements in the awake task made him feel helpful:

> Craig: ... you do feel helpful, like your helping them, they're asking a question, your giving an answer, it's kind of a two way street

In contrast Jen appeared to find completing the task slightly more stressful:

> Jen: ...in my mind I think I thought, that I've got to make sure that I give the correct answer, got to give exactly what they need to know, I think I was quite aware of that, umm when they kept saying to me can you feel it now can you move it, I knew, I don't know how I knew, but I knew that I had to say yes or I knew that I had to say no, and you know I was fully aware that I had to give them in depth answers umm and and I think I knew why they needed to know, as in obviously they needed to know so they knew the operation was going well so your sort of very aware of that going on if that makes sense

It was interpreted that the most abnormal part of the operation for participants was that they found it normal:

> Rachel: ...I couldn't get my head around how I could be awake and totally compus mentus but not feel any pain

> Sundeep: ... it's unbelievable, I'm here, I'm in the theatre, my heads open, skull is open, chatting to this woman as if nothing's happening [laughs]

> Jo: ... so y'know I was probably expecting worse than what it [awake craniotomy] was actually like

Some participants attributed this to the medication:

> Emma: ...it's a bit like having a drunken conversation really because umm, I was obviously, y'know, on my lots of umm [pause] well whatever they'd put me on, paracetomols and all sorts of things being pumped in but umm

> Sundeep: ...I was perfectly comfortable, I suppose because I was drugged up as well [laughs] that's something to do with it

Or the communication:

> Sundeep: ...the communication was very good, communication is one of the most important aspects, I thought, and and yeh each point they were communicating to me, asking me how I was doing, how I'm feeling, hum yeh so on awaking I think I was I was made comfortable, hum and people told me exactly what was going on I was I was happy with that

Ben and Emma go on to rationalise why they found the operation so normal:

> Ben: ...it's a fairly major operation, you see all through this experience, I've never really considered it a major operation, everyone else has but not me, I don't know why, it's just I've been reassured, when I was awake down there it was like being in the dentist so what's the big deal you know

> Emma: ...I just think it's just cos it's probably just a lot of worse than it sounds, it's probably to sum it up it just like yeh, y'know, sounds horrendous but it's not y'know

> Emma: ...I just said oh God, I feel like I'm at the dentist

Rachel expressed that her perception of the experience could have changed over time:

> Rachel: ...I sometimes do think that maybe now I say oh that wasn't so bad because I got the result out of it I wanted and erased some bits so I think you've built it up to be so terrible that when it's not terrible its instantly good...you don't care if there were bits that were crappy because it wasn't as bad as what you thought...I thought this is gonna be horrendous, it's going to be terrible, I'm gonna take weeks to recover

In summary it was understood that in retrospect the participants found the awake craniotomy a very normal experience. However given the extract from Rachel above, caution should be taken when generalising or comparing the data. *[See 5.5 for further discussion on study limitations]*

4.2 Added subtheme for *information*

Involving the family.

At times throughout the interviews participants made references to their families. Although their experience of awake craniotomy did not appear to be contingent on their families, extracts led to the interpretation that they were an important aspect. Given the extract from Jen in the journal paper about the lack of information for family and friends, extracts illustrating the importance of the family will be presented.

Some of the participants discussed relying on their family for support

> Sundeep: ... so it was decided that I was going to move in to my parents, for a while, for two weeks or so, they could look after me

> Jo: ...my mum stayed...overnight in a hotel nearby, which was good because at least it meant they were there and stuff so yeh that was good

The women particularly considered their children during the process:

> Emma: ...I'd rather it be me than them n so y'know be y'know taking it on myself, than, them having to deal with me, so I was just, yeh, that's how I thought about it

> Jen: ... I didn't want them to come and visit [Jen's children], didn't think it was very fair, they were only young, quite young, so that was the first time I saw them [when she got home after the operation]...it felt very good

Participants considered how their family must have felt:

> Sundeep: ...so on the morning, my parents came in, I think my family members [pause], I sensed that they were sort of [pause] sc [scared], not scared, I wouldn't say scared but anxious, umm y'know

> Emma: ...he slept in the chair... my mum had the kids but he just didn't [saying her husband didn't leave the hospital when she was having seizures prior to the awake craniotomy] I mean when you're seeing someone seizuring all the time...he probably just thinks, God she might not be there

> Rachel: ...I think it's worse for everybody else, like your family and stuff, than it is for yourself

Most participants put themselves in the position of their family:

Emma: ...If I was in their shoes I can see me blubbering at the bedside, n this that and the other, I was sort of a bit like stop crying

Jo: ...I remember afterwards he [Richard Hammond – TV presenter, after his car accident] wrote his autobiography and y'know like reading that, n like how it was, m his wife's experiences and I remember thinking oh my God that's how they [Jo's family] must've felt, so yeh [begins to cry], that's quite upsetting cos I think it must've been worse for them really in a way

Participants relying on their family, considering their families feelings and placing themselves in their shoes emphasises the need to involve the family in information from the department of neurosurgery. It was understood from the above extracts that the family goes through the experience with the participant. Therefore they have a right to understand each aspect of the awake craniotomy experience.

5.0 Discussion

The discussion will expand on the information in the journal paper. As anticipated in IPA research, much of the literature presented in the discussion was not discussed in the introduction section to this study. This is attributable to the idiographic nature of IPA and the focus on the themes emerging from this sample of participants (Smith et al. 2009). Although the extended discussion is structured in a similar way to the journal paper the interconnected nature of the identified themes and the addition of two new subthemes, means that information presented will often overlap in different sections. To resolve this, and avoid duplication, the reader will be directed to the section which best explores what is being discussed. Implications and recommendations for future research will be presented throughout the discussion.

5.1.1 Self-preservation in previous awake craniotomy studies

The emphasis placed on self-preservation in the current study, in contrast to Palese et al. (2008), could be attributable to the differences in the time frame of the two studies, for example Palese et al. (2008) interviewed participants prior to awake craniotomy, or the interpretative element in IPA (Smith, 1996). Thus as participants alluded to adopting self-preservation strategies throughout their entire experience it was interpreted as an important part of their experience. Differences in analytic journeys, for example thematic and phenomenological analysis in contrast to IPA, could also be the catalyst for further differences between the current study and the two previous qualitative studies (Khu et al. 2009; Palese et al. 2008). *[See 3.1.4 for further discussion on alternative approaches to analysis]*

The interpretations made in the current study, that participants adopted self-preservation strategies due to their understanding of the potential consequences, supports a theme identified in Khu et al. (2009): "patients understood the rationale behind awake surgery" (p. 4). Khu et al. (2009) discussed a gradual acceptance of the awake craniotomy by participants as they gained more information from the neurosurgeon. The authors reported

that at the time of the awake craniotomy participants understood why they needed to have the operation awake rather than under general anaesthetic.

5.2 Operation experience

The findings in the current study support previous research reporting that participants do not place a lot of emphasis on the awake craniotomy procedure itself (Khu et al. 2009). Khu et al. (2009) reported a theme "patients were more concerned about the disease process than the procedure" (p. 4). However Palese et al. (2008) discussed the experience as a more anxiety provoking experience, with an explicit focus on the physical aspects of the operation.

5.2.1 Relationship with the neurosurgeon and operation environment

The importance of the relationship has also drawn comparison with psychotherapy literature (Lambert & Barley, 2001). It was reported that specific therapy techniques do not provide a major contribution towards successful therapeutic outcomes, rather these are attributable to the therapeutic relationship. In the current study the positive experience of awake craniotomy was not interpreted as dependent upon the physical characteristics, for example concrete information or the noise in the operation, but attributable to the *relationship with the neurosurgeon*.

5.2.3 Summary

There is contrasting literature available regarding the participant tolerance of awake operations. It appears that the participants in the current study found the awake craniotomy tolerable however it was interpreted that this was facilitated by their *relationship with the neurosurgeon*. The contrast in the literature could represent different neurosurgeons, it could represent the differences between the participants in individual studies or it could represent the variations in time of data collection. With so many unanswered questions it is clear that further research needs to focus on exploring the experience of awake craniotomy further.

To do this, additional qualitative studies could be conducted within the awake craniotomy population, specifically within the UK. This could develop a literature base to represent if the physical aspects of the operation are important to the participants through allowing them the opportunity to speak freely. For example more studies utilising semi-structured or unstructured interview schedules. If as in the current study and Khu et al. (2009) participants place greater emphasis on other parts of the experience these should begin to be considered more closely. This clearly has implications for the future of awake craniotomy particularly in relation to the patient-neurosurgeon relationship, as well as implications for conducting alternative awake surgeries (Zanchetta & Bernstein, 2004) and for the role of neurosurgeons and nurses who have to work with patients during the procedure (Chit Ying et al. 2001).

5.3 Information

It was understood that participants in the current study needed additional information to help them to understand the operation procedure and operation outcomes. This supports research reporting that 38% of patients are unhappy with the amount of information they are given about their illness (Lidstone et al. 2003). The lack of concrete information reported in the current study is consistent with Royal College of Physicians guidelines (Davies & Hopkins, 1997; Davies & Hopkins, 1997b) which recommend that neurosurgery departments need to improve their information provision. More recently this need has been reiterated in a systematic review of the provision of information for adults with high grade brain tumours (Davies & Higginson 2003) and in NICE guidelines (2006).

The current study shows partial support for Khu et al. (2009). Khu et al. (2009) reported that participants obtain information via the neurosurgery team and the internet. However Khu et al. (2009) did not report that participants asked for concrete information. In addition the current study is consistent with research suggesting that patients with low and high grade brain tumours avoid concrete information (Dunkel-Schetter, Feinstein, Taylor & Falke, 1992; Maes, Lewenthal & Ridder, 1996). The current findings do not support research exploring coping strategies and Parkinson disease patients prior to neurosurgery (Montel &

Bungener, 2008). Montel and Bungener (2008) reported that participants were most likely to utilise instrumental coping strategies, including seeking out information, prior to neurosurgery. The different conclusions drawn by these two studies could represent the differences between the health conditions under investigation.

The current study showed some support for research suggesting that information and preparation impact on the surgical experience however in contrast to previous research they were not interpreted as essential to the surgical experience (Gnanalingham & Budhoo, 1998; Moritz-Gasser & Duffau, 2010). Moritz-Gasser & Duffau (2010) reported that participants would have a satisfactory perception of the operation if they have clear information of the role they were playing during the operation. Additionally if they did not have this information the authors proposed that this anxiety would increase. In the current study the participants reported being satisfied with the awake craniotomy. However some support is shown for the role information could play in reducing apprehension during the operation (Lee, Chui & Gin, 2003; Johansson, Nuutila, Virtanen, Katajisto & Salantera, 2005; McKenna, 1997).

5.3.1 Involving the family

The current study proposed that participants drew on their family for support during their experience of awake craniotomy. This is not reflected in the two previous qualitative studies (Khu et al. 2009; Palese et al. 2008). However support is shown for previous phenomenological research reporting that the family is used as a source of support for brain tumour patients (Poon, 2005). The findings in the current study also suggest that the women particularly focused on their children. This supports research suggesting that brain tumour patients create meaningfulness through their family (Strang & Strang, 2001).

The findings in the current study also support Axelrod & Dorr Goold (2000) who reported that families, as well as patients, need to develop trust in the surgeon. Fox and Lantz (1998) through a thematic analysis identified "my family has a brain tumour" (p. 245) as a key theme. This represents the impact of a brain tumour diagnosis for the rest of the family. Thus Weston and Weston (2006)

report the importance of communicating knowledge, perspective and advice to both patients and families as crucial to patient care.

5.3.2 Summary

Although guidelines (Davies & Hopkins, 1997; Davies & Hopkins, 1997b; NICE, 2006) have outlined a need for improved information for high grade tumour patients, the current study shows no support for the provision of concrete written information for patients. Little is known about what type of information participants would prefer (NICE, 2006). Therefore further research could explore this within a brain tumour population. This combined with a finding that doctors and nurses have low ability to recognise patient need (Cancer guidance subgroup, 1998) means that allowing patients, and their families, access to concrete information is crucial (NICE, 2006).

In addition some of the studies conducted have alluded to the client group when considering information, for example the cognitive or memory difficulties associated with having a brain tumour (Lidstone et al. 2003). Although this does not appear to be relevant to the participants in this study, this should be taken in to consideration. This is a further reason for the provision of written information, involving patient's families and enhancing creativity in practice. For example, a recent report on patients with lung cancer suggested that, when mindful of patient preference, recording the consultation sessions for the patients can be a positive source of information (Cancer Guidance Subgroup, 1998). Information for participants could also incorporate ideas for self-preservation strategies to help patients to cope with their brain tumour and upcoming awake craniotomy. If the literature was improved in this area, this could generate some useful strategies for patients.

5.5 Strengths and limitations

Using IPA to explore the patient experiences of awake craniotomy was a particular strength of the study. My analytic attention has focused on the participants' attempts to make sense of their awake craniotomy experiences. In

doing so I feel I have moved between the individual accounts and the shared accounts and from the descriptive account offered by the participant during the interview to an interpretation. This has revealed aspects of the experience which are important for the participants going through the procedure. Due to my epistemological position and the subjectivity of IPA, the claims I have made are tentative however the process of reaching them has been systematic and rigorous. This is displayed in the journal paper through its accessibility for the reader.

In addition, unlike previous qualitative studies (Khu et al. 2009; Palese et al. 2008) the single semi-structured interview conducted in the participants' own homes, did not create a superficial split. In addition the questions did not direct participants to discuss a particular aspect of their experience or ask the participants for an honest account of the experience in the environment of the neurosurgery team. This has ensured that the participants' perception of their experience, at the time of the interview, was construed throughout the analysis and is emphasised in the final write up. In addition conducting interviews at the participants' own homes was viewed as a particular strength of this study. This allowed participants a personal space to discuss their experiences. This may have enhanced how comfortable the participant felt during the interview and potentially added depth to the data obtained.

In addition to the limitations extensively discussed in the journal paper, as well as the limitations which apply more generally to the use of IPA analysis, a final consideration is of the researchers experience using qualitative research. This study is my first attempt at completing an IPA study. I have conformed to quality guidelines, kept a comprehensive audit trail and reflective diary and utilised supervision when and where appropriate. However, Smith et al. (2009) proposed that researchers develop their IPA skills over time (Smith et al. 2009). *[See section 3.1.4 for IPA critique]*

5.6 Critical reflective component

To complete my doctoral thesis a critical reflection on my research project will be presented. This reflection will consider the scientific, ethical and theoretical issues which have been raised through the production of my research.

5.6.1 Scientific issues.

My journal paper 'An interpretative phenomenological analysis of the patient experience of awake craniotomy: brain tumour diagnosis to discharge' was written for submission to the 'Journal of Neurosurgery'. Therefore when considering the scientific issues raised by my research I felt it would be crucial to critically reflect on how my journal paper, utilising qualitative methodology, could attempt to integrate with the dominant medical discourse in neurosurgery departments and journals.

I knew instinctively that given the paucity in the literature, my target audience and the topic of my work, that my article would be better placed in a neurosurgery journal. However when searching the literature for research on the awake craniotomy it appeared that the dominant discourse was around the safety of the patient in the operating theatre. Thus research focused on comparisons across anaesthesia techniques and addressed complications that may arise through the procedure. This induced insecurity within me I reflected on this in my reflective diary:

> "I'm asking people which journal to submit to. It feels right to submit to a neurosurgery journal however this is dominated by jargon that I am struggling to understand. Where would I start in keeping up with the medical jargon? Or should I write for the journal in my own words. Give them something to read about which makes sense and is applicable. Something other than the statistical effects of remifentanil and fentanyl in conjunction with propofol!? Or is that the point. I don't understand their language and can find no use for it from a psychological perspective. Rather than their discourse being inaccessible to me, my discourse, particularly as I am using IPA, would that be inaccessible to them. Will neurosurgeons see the study and brush past it?"

Since the excerpt in the reflective diary was written I have come to accept that the dominant medical discourse discussed exists alongside the knowledge that throughout their studies neurosurgeons have made attempts at establishing patient satisfaction (e.g. Danks et al. 1998). In addition, more recent attempts

have been made to explore the patient experience of the awake craniotomy (Khu et al. 2009; Palese et al. 2008) and have been granted publication in neurosurgery journals: Acta Neurochirurgica and Journal of Neurosurgery. Therefore it was hoped that the fundamental importance of qualitative research in medical journals (Black, 1994), has been recognised through the welcoming of the research in to the neurosurgery arena, providing information for neurosurgeons that they were struggling to collect themselves. This is summarised in a quote from Reicher (2000):

"...if something is defined and understood by reference to its [qualitative research] limits, then understanding the domain in which quantitative methods should not be used, leads to a more profound understanding of when and how such methods [qualitative] should be used" (p. 2).

In reality, qualitative work in neurosurgery journals is rare and so it is difficult to establish how much of an impact previous research has actually made on neurosurgery departments. In an attempt to overcome this issue during my research I have made an active effort to build a relationship with the Department of Neurosurgery, particularly with the neurosurgeons. This research evolved from a request from the neurosurgeon for a study examining patient experiences of awake craniotomy. It was highlighted that an understanding of the experience could be beneficial to the department and departments around the UK. I have attempted to capture and retain this interest through constant communication with the neurosurgeons involved. This has included any decisions I have made about the methodology, for example deviating from the neurosurgeons quantitative ideals to qualitative methodology, outlining the type of analysis I have conducted, the recruitment of participants, the progress of the study and the timeline of completion. I have also encouraged the neurosurgeons to discuss the research with their colleagues.

To understand the importance of involving the neurosurgeons I reflected on my relationships with my clinical psychology colleagues. This helped me to consider the importance of building a rapport with neurosurgeons with the hope that the nature of the research would be passed on informally to their medical colleagues. Therefore to establish momentum for the current research it was

felt that emphasis needed to be developed from the inside out. On submission of my doctoral thesis my work to establish credibility with the neurosurgery department will not end. I plan to meet with the neurosurgeons to feedback the research and gain their comments and ideas for disseminating the research. I will then act on these ideas. In addition, I intend to share the research with other clinical psychologists through the NHS Trust's quarterly research meeting. It is hoped that developing recognition amongst clinical psychologists about the transference of the positive effects of patient-clinician relationships to our medical colleagues could bridge the gap with the medical model. Thus recognising how to work together to capitalise on the strengths of each tradition.

5.6.2 Ethical issues.

A key ethical issue raised in my research study was the balance between asking participants to discuss a topic which may cause them distress and the ability to produce a research study which may have benefits for future patients. It has been proposed that there are benefits to taking part in research, for example validating the participants' experience, empowering patients through research and interviews having a cathartic effect and promoting healing (Hutchinson & Wilson, 1994). Despite the reported benefits my first participant withdrew following becoming distressed, leading me to reflect on the ethics of the study:

> "The participant becoming distressed, I felt in control, I could manage what was happening but still it makes me question if it's all worth it. It makes me sad that the outcome will not impact his experience, it won't change it for him. But I suppose that's the point use peoples past experiences to improve others future ones. If I consider my family or me, if I had a bad experience I would want to know it could be better for others wouldn't I?"

The study had passed through the NHS ethics committee so I was fully aware of the contingencies if a participant became distressed. As a trainee clinical psychologist I was able to provide a sufficient level of support to the participant and I also redirected the participant to alternative sources of contact. As this interview was the first interview I conducted it made me more mindful of the

potential distress the interviews could cause and I was vigilant in identifying participant distress and offering breaks. I reflected on this in my reflective diary:

> "…I am about to go in to my 2nd interview. I have turned up early. I am feeling somewhat apprehensive about it given how the first interview went. However at least I can see that I know how to handle it. I wasn't expecting it last time but I managed it well. I was able to follow my procedure. I also know the importance of not rushing in to the interview now. I was trying to slow down in the last interview with my consent form but I think I might take it even slower this time. Get a feel for the atmosphere and her personality before we begin"

The withdrawal of a participant also brought me closer to the research and the analysis process. Thus I treated the data with the upmost respect, adhered to quality guidelines and ensured that each participant was represented through the write up of the study. On completion of my doctoral thesis I will ensure that the data is treated with respect through actively disseminating the research and storing the information safely.

I also considered the power imbalance throughout my research process. Thus I became very aware that participants had taken part in an interview and then it was in my hands to analyse and interpret their accounts. At one stage in my write up I became very conscious of if the participants ever got to read my journal article:

> "...I'm writing my interpretations and writing up what I have found which I feel confident about. I feel confident that I have stayed true to the participant data and that I have done justice to those who took part. However I cannot get away from wondering what participants would think if they read the full article. I will send them a summary but its' not the same. What would they think?"

As discussed in the extract from my diary I am overcoming some of the anxiety about participants through sending each participant a summary of the study. Considered together the ethical implications and the potential power imbalance leave me, and other researchers, in a position of power. The findings from my

study have helped me to understand the utility of qualitative research, whilst simultaneously developing a greater respect for the complex NHS ethics procedure that the study went through at the start of the research, as well as the audit trail and reflective diary kept throughout the experience. Thus research should be appropriately planned, with implications for potential participants thought out and quality criteria adhered to.

5.6.3 Theoretical issues.

A key theoretical issue to evolve from my research is the paradox between qualitative methodology and writing a journal paper for publication. When developing my understanding of qualitative methodologies I became aware of the evolving nature of qualitative enquiry as crucial to the analysis process. This was particularly poignant due to the double hermeneutic and the iterative process of IPA (Smith et al. 2009). Throughout the analysis process I became intertwined with the analysis process, fluctuating between being close to the data and distant from it. Throughout the study I relished the interplay between myself and the data. I wrote about this in my reflective diary:

> "...everything I have read about, particularly the hermeneutic cycle is being played out as I speak. I am so in touch with my data. I feel as though I become completely absorbed, and feel a need to get out. When out I can tolerate this for a short while but then I must go back in. I have gathered momentum in this process and am finding it difficult to know when to stop"

As a researcher I used my own experiences to inform my analytic process. However, when it came to writing up my research I became aware that what I would write in my journal paper would be a snapshot of my analysis, thus analysis is rigid on completion of the write up. This presented to me the paradox between the nature of qualitative enquiry and the pragmatic need to communicate what we find in our research. I reflected on this in my reflective diary:

> "...I don't know when to stop my analysis. I have been trying to write up my results section for what feels like a long time now but it is still evolving. I consulted the IPA text book and I am right, the analysis

should continue through the write up but where do I stop? How will I know enough is enough and move on to the discussion because if I carry on like this I will never reach my discussion? And what point is there in presenting results without any implications?"

Although I appreciate the evolving nature of IPA I equally value the importance of communicating our research findings. These should be accessible and honest. I will attempt to overcome this paradox through presenting my research to various groups within the NHS, attempting to accompany my research with an understanding of IPA methodology.

5.7 Conclusions

The paucity and methodological weaknesses of previous literature investigating the patients' experience of awake craniotomy formed the rationale for the current study. In support of this research the current study has shown that it is important for the neurosurgical team to develop an understanding of the patients' experience. It has been suggested through the current study that the awake craniotomy procedure is not the priority for the patient (Khu et al. 2009). Instead the interconnection of others aspects, for example *self-preservation* prior to the operation, the *relationship with the neurosurgeon* throughout the experience and the need for different types of *information* play more of a paramount role.   This should inform the direction of future research.

It is hoped that the emphasis of the current study on the *relationship with the neurosurgeon* during awake craniotomy will develop an understanding for neurosurgeons about the importance of their role. In doing so neurosurgeons should recognise the positive effects of their input, for example containing patient apprehension, whilst keeping in mind that the relationship should not act as a substitute for concrete forms of *information,* thus affecting patient choice. On a wider scale it is hoped that the submission of a qualitative study to a neurosurgical journal will not only add to the literature on awake craniotomy, but also encourage further publication of qualitative research in the medical world.

References

Adelbratt, S., & Strang, P. (2000). Death anxiety in brain tumour patients and their spouses. *Journal of palliative medicine, 14*(6),   499-507.

Armstrong, T. S. (2004). Introductions to brain tumour series. *Seminars in oncology Nursing, 20*(4), 221-223.

Axelrod, D. A., & Dorr Gould, S. (2000). Maintaining trust in the surgeon patient relationship: challenges for the new millennium. *Archive of surgery, 135,* 55-61.

Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: establishing 'rigour' in interview analysis. *Transactions, institute of British geographers, 22,* 505-25.

Bhaskar, R. (1975). *A realist theory of science.* West Sussex, England: Harvester Press.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative   phenomenological analysis (IPA): A qualitative methodology of   choice   in   healthcare research. *Qualitative research in psychology, 5*(3), 214-224.

Bigner, D., McLendon, R., & Bruner, J. (1998). *Russell and Rubinstein's pathology of tumours of the nervous system.* (6th Ed.). London, England: Arnold.

Black, N. (1994). Why we need qualitative research – Editorial. *Journal   of epidemiology and community health, 48,* 425-426.

Bradley, S., Sherwood, P. R., Donovan, H. S., Hamilton, R., Rosenzweig, M., Hricik, A et al. (2007). I could lose everything: understanding the cost of a brain tumor. *Journal of neuro-oncology, 85*(3), 329-338.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*, 77-101.

Brocki, J. M., & Weardon, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and health*, *21*, 87-108.

Burker, E. J., Madan, A., Evon, D., Finkel, J. B., & Mill, M. R. (2009). Educational level, coping, and psychological and physical aspects of quality of life in heart transplant candidates. *Clinical transplantation, 23*(2), 233-240.

Cancer Guidance Subgroup of the Clinical Outcomes Group. (1998). *Improving outcomes in lung cancer – the research evidence*. Leeds, England: NHS Executive.

Carver, C. S., Pozo, C., Harris, S. D., Noriega, V., Scheier, M. F., Robinson, D et al. (1993). How coping mediate the effect of optimism on distress: a study of women with early stage breast cancer. *Social psychology, 65*(2), 375-390.

Cassileth, B. R., Lusk, E. J., Miller, D. S., Brown, L. L., & Miller, C. (1985). Psychosocial correlates of survival in advanced malignant disease? *New England journal of medicine, 312,* 1551-1555.

Cella, D. F., Jacobson, P. B., Orav, E. J., Holland, J. C., Superfarb, P. M., & Rafla, S. (1987). A brief POMS measure of distress for cancer patients. *Journal of chronic disease, 40,* 938-942.

Chit Ying, L., Levy, V., Shan, C.O., Wing Hung, T., & Kit Wah, W. (2001) A qualitative study of the perceptions of Hong Kong Chinese women during caesarean section under regional anaesthesia. *Midwifery, 17*(2), 115-122.

Costello, T. G., & Cormac, J. R. (2004). Anaesthesia for awake craniotomy: a modern approach. *Journal of clinical neuroscience, 11*(1), 16-19.

Croyle, K. L., Troster, A. L., Fields, J. A., Straits-Troster, K. A., Lyons, K. E., & Pahwa, R. (2003). Presurgical coping, depression, and quality of life in persons with Parkinson's disease. *Journal of clinical psychology in medical settings, 10(*2), 101-107

Danks, R. A., Rogers, M., Aglio, L. S., Gugino, L. D., & Black, P. M. (1998). Patient tolerance of craniotomy performed with the patient under local anaesthesia and monitored conscious sedation. *Neurosurgery, 42*(1), 28 -36.

Danks, R. A., Aglio, L. S., Gugino, L. D., & Black, P. M. (2000). Craniotomy under local anaesthesia and monitored conscious sedation for the resection of tumors involving eloquent cortex. *Journal of neuro oncology 49,* 131-139.

Davies, E., & Higginson, I. J. (2003). Communication, information and support for adults with malignant cerebral glioma: a systematic literature review. *Supportive care in cancer, 11,* 21-29.

Davies, E., & Hopkins, A. (1997). Good practice in the management of adults with malignant cerebral glioma: clinical guidelines. *British journal of neurosurgery, 11,* 318– 330.

Davies, E., & Hopkins, A. (1997b). *Improving care for patients with malignant cerebral glioma.* London, England: Royal College of Physicians.

Davis, F. G., Kupelian, V., Freels, S., McCarthy, B., & Surawicz, T. (2001). Prevalence estimates for primary brain tumours in the Unites States by behavior and major histology groups. *Neuro-oncology, 3,* 152– 158.

De Andres, J., Valia, J.C., Gil, A., & Bolinches, R. (1995) Predictors of patient satisfaction with regional anesthesia. *Regional anesthesia, 20*(6), 498 - 505.

DeGroot, K. I., Boeke, S., Bonke, B., & Passchier, J. (1997). A re evaluation of the adaptiveness of avoidant and vigilant coping with surgery. *Psychology and health, 12,* 711–717.

Department of Health. (1997). The Caldicott committee: the report on the review of patient identifiable information. Department of Health.

Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. *Health psychology, 11,* 79–87.

Edvardsson, T., & Ahlstrom, G. (2005). Illness-related problems and coping among persons with low-grade glioma. *Psycho-oncology, 14*(9), 728-737.

Elliot, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British journal of clinical psychology, 38,* 215-229.

Finlay, L. (2009). Debating phenomenological research methods. *Phenomenology and practice, 3*(1), 6-25.

Flowers, P., Duncan, B., & Frankis, J. (2000). Community, responsibility and culpability: HIV risk management amongst Scottish gay men. *Journal of community and applied social psychology, 10*, 285-300.

Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *The American psychologist, 55*, 647–654.

Fox, S., & Lantz, C. (1998). The brain tumour experience and quality of life: a qualitative study. *Journal of neuroscience nursing, 30,* 245–252.

Gilbert, M., Armstrong, T., & Meyers, C. (2000). Issues in assessing and interpreting quality of life in patients with malignant glioma. *Seminars in oncology, 27*, 20–26.

Gilligan, B. (1993). A positive coping strategy. Humour in the oncology settings. *Professional nurse, 8*(4), 231-223.

Giorgi, A., & Giorgi, B. (2008). Phenomenology. In. J. A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods* (2nd Ed.) (pp. 26-53). London, England: Sage publications.

Glaus, A., Crow, R., & Hammond, S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. *Supported care in cancer, 4*(2), 82-96.

Gnanalingham, K. K.. & Budhoo, M. (1998). Day case hernia repair under local versus general anaesthetic: patient preferences. *Ambulatory surgery, 6*(4), 227–229.

Goebel, S., Nabavi, A., Schubert, S., & Mehdorn, H. M. (2010). Patient perception of combined awake brain tumor surgery and intraoperative 1.5T magnetic resonance imaging: the Kiel experience. *Neurosurgery, 67*(3), 594-600.

Grant, R., & Metcalfe, S. E. (2004) Biopsy versus resection for malignant glioma. *The Cochrane library*, *3*, CD002034.

Hammersley, M. (2000). *Taking side in social research: essays on partisanship and bias.* London, England: Routledge.

Heimans, J. J., & Taphoorn, M. J. B. (2002). Impact of brain tumour treatment on quality of life. *Journal of neurology, 249,* 955-960.

Husserl, E. (1970). *The crisis of European sciences and transcendental phenomenology.* Illinois, USA: North Western University Press.

Hutchinson, S., & Wilson, H. (1994). Research and therapeutic interviews: a poststructuralist perspective. In. J. M. Morse (Ed.). *Critical issues in qualitative research methods*. London, England: Sage Publications.

Institute for Scientific Information. (1996). *1996 Science Citation Index. Journal citation reports.* Philadelphia: Institute for Scientific Information.

Johansson, K., Nuutila, L., Virtanen, H., Katajisto, J., & Salantera, S. (2005). Pre-operative education for orthopaedic patients: systematic review. *Journal of advanced nursing, 50*(2), 212-223.

Jukich, P.J., McCarthy, B. J., Surawicz, T. S., Freels, S., & Davis, F. G. (2001). Trends in incidence of primary brain tumours in the United States, 1985 1994. *Journal of neuro-oncology, 3*, 141-151.

Kess, J. F. (2001). Review of humour: The psychology of living buoyantly. *Canadian psychology, 42*(3), 232-234.

Khalili, Y. (2007). Ongoing transitions: the impact of malignant brain tumour on patient and family. *Axon, 28*(3), 5-13.

Khu, K. J., Doglietto, F., Radovanovic, I., Taleb, F., Mendelsohn, D., Zadeh, G et al. (2009). Patient's perceptions of awake and outpatient craniotomy for brain tumour: a qualitative study. *Journal of neurosurgery, 10,* 1-5.

Kim, H. S., Yeom, H. A., Seo, Y. S., Kim, N. C., & Yoo, Y. S. (2002). Stress and coping strategies of patients with cancer: a Korean study. *Cancer nursing, 25*(6), 425-431.

Klein, M., Taphoorn, M. J. B., Heimans, J. J., Van der Ploeg, H. M., Vandertop, W. P., Smit, E. F et al.(2001). Neurobehavioral status and health-related quality of life in newly diagnosed high grade glioma patients. *Journal of clinical oncology, 19*, 4037-4047

Kuiper, N. A., Martin, R. A., & Olinger, L. J. (1993). Coping humour, stress, and cognitive appraisals. *Canadian journal of behavioural science, 25*(1), 81 - 96.

Kvale, S. (1996). *Interviews: an introduction to qualitative research interviewing.* London, England: Sage publications.

Lambert, M. J., & Barley, D. E. (2001). Research Summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy, 38*(4), 357 -361.

Lanier, W. L. (2001). Brain tumour resection in the awake patient. *Mayo clinical proceedings, 76,* 670-672.

Larkin. M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology, 3*(2), 102-120.

Larkin, A. C., Cahan, M. A., Whalen, G., Hatem, D., Starr, S., Haley, H. L et al. (2010). Human emotion and response in surgery (HEARS): A simulation-based curriculum for communication skills, systems based practice, and professionalism in surgical residency training. *Journal of American college of surgeons, 211*(2), 285-292.

Laungani, P. (2003). Therapeutic strategies for coping with a life threatening illness: a personal testament. *Illness, crisis & loss,11*(2), 162-182.

Lee, A., Chui, P. T., & Gin, T. (2003). Educating patients about anesthesia: a systematic review of randomized controlled trials of media-based interventions. *Anesthesia and analgesia,96*(5), 1424–1431.

Lidstone, V., Butters, E., Seed, P. T., Sinnott, C., Beynon, T., & Richards, M. (2003). Symptoms and concerns amongst cancer outpatients: identifying the need for specialist palliative care. *Palliative medicine, 17*, 588 595.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic enquiry.* Newbury Park, CA: Sage Publications.

Livneh, H. (2000). Psychosocial adaptation to cancer: The role of coping strategies. *The journal of rehabilitation,* 66(2): 40–49.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. *British journal of psychology, 91,* 1 20.

Maes, S., Lewenthal, H., & Ridder, D. T. D. D. (1996). Coping with chronic diseases. In M. Zeidner., & N. S. Endler. (Eds.), *Handbook of coping theory, research, applications.* Wiley: New York; 221–251.

Manninen, P. H., Balki, M., Lukitto, K., & Bernstein, M. (2006). Patient satisfaction with awake craniotomy of tumour surgery: a comparison of remifentanil and fentanyl in conjunction with propofol. *Neurosurgical anaesthesia, 102,* 237- 242.

Marsh, H. (2005). Low-grade gliomas in adults. In A. J. Moore., & D. W. Newell. (Eds.). *Neurosurgery: principles and practice.* (pp. 155-166). London, England: Springer-Verlag Limited.

McIlfatrick, S., Sullivan, K., & McKenna, H. (2006). What about the carers?: exploring the experience of caregivers in a chemotherapy day hospital setting. *European journal of oncology nursing, 10*(4), 294-303.

McKenna, D. (1997). A focus on the five senses of the day surgery patient: a quality assurance initiative. *Ambulatory surgery,5*(2), 61–65.

Mental Capacity Act of 2005, c. 9. (2005). Retrieved May 6th, 2010 from http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1.

Meyer, F. B., Bates, L. M., Goerss, S. J., Friedman, J. A., Windschiti, W. L., Duffy, J. R et al.(2001). Awake craniotomy for aggressive resection of primary gliomas located in eloquent brain. *Mayo clinic proceedings, 76,* 677-687.

Mitchell, M. (2008). Patient anxiety and modern elective surgery: a literature review. *Journal of clinical nursing, 12,* 806–815.

Montel, S., & Bungener, C. (2008). What relation is there between deep brain stimulation and coping strategies in Parkinson's disease? *Movement disorders, 23*(12), 1780-1784.

Moritz-Gasser, S., & Duffau, H. (2010). Psychological consequences of awake brain tumour surgery. *Psycho-oncologie, 4*(2), 96-102.

National Institute for Clinical Excellence (2006). Improving outcomes for people with brain and other CNS tumours – the manual. *NICE cancer service guidance.*

Ogungbo, B. I., Najim, O., Mendolow, P. J., & Crawford, P. J. (2002). Epidemiology of adult brain tumors in Great Britain and Ireland. *British journal of neurosurgery, 16,* 140-145.

Osoba, D., Brada. M., Prados, M. D., & Yung, W. K. A. (2000). Effect of disease burden on health-related quality of life in patients with malignant gliomas. *Neuro-oncology, 1*, 221–228.

Palese, A., Skrap, M., Fachin, M., Visioli, S., & Zannini, L. (2008). The experience of patients undergoing awake craniotomy: in the patients' own words: a qualitative study. *Cancer nursing, 31*(2), 166-172.

Pelletier, G., Verhoef, M., Khatri, N., & Hagen, N. (2002). Quality of life in brain tumor patients: the relative contributions of depression, fatigue, emotional distress, and existential issues. *Journal of neuro-oncology, 57*(1), 41-49.

Petersen, S., Heesacker, M., & DeWitt Marsh, R. (2001). Medical decision making among cancer patients. *Journal of counselling psychology, 48*(2), 239-244.

Pobereskin, L. H., & Chadduck, J. B. (2000). Incidence of brain tumours in two English counties: A population-based studies. *Journal of neurology, neurosurgery and psychiatry, 69,* 464-471.

Poon, C. S. (2005). Care giving for loved ones with a brain tumour. *Dissertation abstracts international, section B, the sciences and engineering, 66*(6), 3468.

Popay, J., & Williams, G. (1998). Qualitative research and evidence based healthcare. *Journal of the royal society of medicine, 91*(35), 32-37.

Punch, K. (2005). Introduction to social research: quantitative and qualitative approaches. Michigan, USA: Sage Publications.

Quinn, M., Babb, P., Brock, A., Kirby, L., & Jones, J. (2001). *Cancer trends in England and Wales 1950–1999: Studies on medical and population subjects No. 66.* London, England: The Stationery Office.

Reicher, S. (2000). Against methodolatry: Some comments on Elliot, Fischer, and Rennie. *British journal of clinical psychology, 39,* -6.

Reijneveld, J.C., Sitskoorn, M. M., Klein, M., Nuyen, J., & Taphoorn, M. J. B. (2001). Cognitive status and quality of life in patients with suspected versus proven low-grade gliomas. *Neurology, 56,* 618–623

Rose, H. A. (2004). *Cancer dictionary.* Miami, Florida: Unicol Inc. Rosenthal, R., & Rosnow, R. L. (Eds.). (1969). *Artifact in behavioral research.* New York, USA: Academic Press.

Sarang, A., & Dinsmore, J. (2003). Anaesthesia for awake craniotomy evolution of a technique that facilitates awake neurological testing. *British journal of anaesthesia, 90*(2), 161-165.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: using interpretative phenomenological analysis in health psychology. *Psychology and health, 11*, 261-271.

Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In. M. Murray & K. Chamberlain (Eds.). *Qualitative health psychology: theories and methods.* (pp. 218 241). London, England: Sage Publications.

Smith, J. A., Michie, S., Stephenson, M., & Quarrel, O. (2002). Risk perception and decision making in candidates for genetic testing in Huntington's   disease: an   interpretative phenomenological analysis. *Journal of health psychology, 7,* 131-144.

Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: a practical guide to research methods.* London, England: Sage Publications.

Smith, J. A. (2004). Reflecting on the development on interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research, 1,* 39-54.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: theory, method and research.* London, England: Sage Publications.

Stommel, M., & Wills, S. (2004). *Clinical research: concepts and research for advanced practice nurses.* London, England: Lippincott, Williams & Wilkins.

Strang, S., & Strang, P. (2001). Spiritual thoughts, coping and 'sense of coherance' in brain tumour patients and their spouses. *Palliative medicine, 15*(2), 126-134.

Thune-Boyle, I. C., Stygall, J. A., Keshtqar, M. R., & Newman, S. P. (2006). Do religious/spiritual coping strategies affect illness adjustment in patients with cancer? A systematic review of the literature. *Social sciences and medicine, 63*(1), 151-164.

Tonn, J. C. (2007). Awake craniotomy for monitoring language function: benefits and limits. *Acta Neurochirurgica (Wien), 149*, 1197 1198.

Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A et al (1997). Standards for research projects and theses involving quantitative methods: suggested guidelines for trainees and courses. *Clinical psychology forum, 108,* 3-7.

Vitaliano, P. P., DeWolfe, D. J., Maiuro, R. D., Russo, J., & Katon, W. (1990). Appraised changeability of a stressor as a modifier of the relationship   between coping and depression: A test of the   hypothesis of fit. *Journal of personality and social psychology, 59,*582–592.

Weitzner, M., & Meyers, C. (1997). Cognitive functioning and quality of   life in malignant glioma patients: a review of the literature.   *Psycho-oncology, 6,*169-177.

Wertz, F. (2005). Phenomenological research methods for counselling psychology. *Journal of counselling psychology, 52*(2), 167-177.

Weston, M. J., & Weston, R. R. (2006). Customer-driven outcomes: a patient and family perspective. *Nursing administration quarterly, 30*(2), 128-132.

Whittle, I. R. (2004). The dilemma of low grade glioma. *Journal of neurology, neurosurgery and psychiatry, 75,* 31-36.

Whittle, I. R., Midley, S., Georges, H., Pringle, A. M., & Taylor, R. (2005). Patient perceptions of "awake" brain tumour surgery. *Acta neurochirurgica, 147*(3), 275-277.

Wideheim, A., Edvardsoon, T., Pahlson, A., & Ahlstrom, G. (2002). A families perspective on living with a highly malignant brain tumor. *Cancer nursing, 25*(3), 236-244.

Willig, C. (2008). *Introducing qualitative research in psychology.* Buckingham, England: Open University Press.

World Health Organisation. (2004). ICD-10, *Classification of mental and behavioural disorders.* Geneva, Switzerland: World Health Organisation.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology& health, 15*(2), 215-228.

Yates, S. J., & Yates, S. (2004). *Doing social science research.* London, England: Sage Publications.

Zanchetta, C., & Bernstein, M. (2004). The nursing role in patient education regarding outpatient neurosurgical procedures. *Axone, 25*(4), 18–21.

Appendices

Appendix A: Cover letter sent out to participants

The Experience of Awake Craniotomy from a Patients' Perspective

Hello,

My name is Kimberley Fletcher. I am currently training to be a Clinical Psychologist with the NHS through the University of Nottingham. The ████████████████████ at the ███████████████████████████ has sent you this information pack on my behalf. I am contacting you because you have had an awake craniotomy procedure and I would like to invite you to take part in my research study.

The purpose of my study is to explore your experience of an awake craniotomy. The study will be the first in the United Kingdom to do this. The aim of the study is to help to 'give voice' to patients, with the goal of promoting an understanding for patients (past, present and future), families, healthcare teams, current and future surgeons and more broadly the NHS. The study will also form my Doctoral Thesis and will go towards my qualification as a Clinical Psychologist.

Please take the time to read the information sheet included. This will tell you a lot more about the study. I have also included an 'opt-in' slip and a stamped addressed envelope. If you would like some more information about the study or if you would like to speak with me to discuss the study further please post this back to me with your contact details and a convenient time to be contacted. I will try my best to get in touch with you at this time. Alternatively if you prefer to use the phone or email please feel free to contact me on **07908 351073** or email me on **lwxkjf@nottingham.ac.uk** and I will get back to you as soon as possible.

Thank you very much for your time,

Best Wishes, Kimberley (Trainee Clinical Psychologist)

Appendix B: Information sheet sent out to participants

Participant Information Sheet

The Experience of Awake Craniotomy from a Patients'
Perspective

Researchers: Kimberley Fletcher (Study Coordinator), Prof. Nadina Lincoln (Chief Investigator), Dr. Roshan das Nair (Academic Supervisor) and Dr. Jamie Macniven (Clinical Supervisor).

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

This sheet will tell you detailed information about the purpose of this study and what will happen to you if you take part. Please feel free to ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part in the study.

What is the purpose of the study?

To explore the experience of patients who have had an awake craniotomy. The study will be the first in the United Kingdom to do this. The aim of the study is to help 'give voice' to patients, with the goal of promoting an understanding for patients (past, present and future), families, healthcare teams, current and future surgeons and more broadly the NHS. The study will also form my Doctoral Thesis which will go towards my qualification as a Clinical Psychologist.

Why have I been invited?

I am interested in your experience of the awake craniotomy procedure and what this means to you. I have contacted you because you have experienced an awake craniotomy. I am hoping to interview around ten awake craniotomy patients to complete the research.

Do I have to take part?

It is up to you to decide. If you do not want to be included in the study your normal treatment will not be affected in any way. If you decide to take part you are still free to withdraw from the study at any time up until 48 hours after the interview has taken place, without giving reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

You will be asked to take part in a semi-structured interview. This interview will last for around one hour. You can have somebody present with you at the interview if you wish. However, this person will be asked not to take part in the interview. You will get to see a copy of the interview themes to have a look at before we conduct the interview.

It is important for you to know that the interview will be audio recorded. This is because I will need to write up the interview, word for word prior to beginning the analysis. The data will be stored on a university computer. The data will be protected by a password and only I will have access to the data. Following this the data will be copied on to a CD and kept in a locked filing cabinet at the University of Nottingham. All data files will be stored anonymously. The data that is gathered will only we viewed in full by myself and my academic supervisor. On submission of the Doctoral thesis quotes will be used directly from the data in the analysis, you will not be identifiable from these quotes.

Before any of this process happens we can discuss this information sheet and you can ask any questions about the study. We can discuss this over the telephone. To arrange this you can post the 'opt-in' slip in the stamped addressed envelope provided. Alternatively if you prefer to use the phone or email you can contact me on **07908 351073** or email me at **lwxkjf@nottingham.ac.uk**. I have included the following diagram to make this clearer for you.

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┌─────────────────────────────────────┐
│                                     │
│  You have received this information │
│  pack telling you about the study   │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  You can return the opt-in slip     │
│  enclosed in the stamped addressed  │
│  evelope to me, or you can contact  │
│  me by telephone or email           │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  I will contact you on your         │
│  preferred time and date to discuss │
│  any questions you have about the   │
│  study                              │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  If you decide that you would like  │
│  to participate we can arrange a    │
│  convinient time and place to       │
│  conduct the interveiw - this can   │
│  be at your own home or you can     │
│  come to the University of          │
│  Nottingham                         │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  I will call you one day before to  │
│  check the interveiw time and date  │
│  is still ok                        │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  I will ask you to sign a consent   │
│  form and we will conduct the       │
│  interview.  Following this you can │
│  ask any questions and you will     │
│  have the opportunity to give me    │
│  any feedback on your involvement   │
│  in the study                       │
│                                     │
└─────────────────────────────────────┘
                  ▼
┌─────────────────────────────────────┐
│                                     │
│  You can receive a summary of the   │
│  study once it has been completed.  │
│                                     │
└─────────────────────────────────────┘
```

Expenses and payments

I hope to meet with you at your own home. However, if you would prefer to meet at the University of Nottingham I will pay reasonable travel expenses.

What are the potential disadvantages and risks of taking part?

As the research is interested in exploring *your* experience of an awake craniotomy there is no defined schedule. Instead the interview will loosely follow a set of questions. This leaves the potential for the interview to provoke sensitive conversation. If this does happen and you feel like you need to take a break from the interview at any time, or stop the interview then that is fine.

What are the possible benefits of taking part?

I cannot promise that the study will help you but I hope that your experiences will benefit patients and healthcare providers in the future.

What if there is a problem?

Any complaint about your participation in the study or any possible harm you might suffer can be reported to the chief investigator.

Will my taking part in this study be confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time up to 48 hours after the interview has taken place. After this time I will begin to transcribe and analyse the data. If you decide to withdraw from the study up to 48 hours following the interview the data will not be used. In either case your routine care will not be affected in anyway.

What if there is a problem?

If you have any concerns about any aspect of the study, you should speak to me and I will do my best to answer your question, my contact number is **07908 351073**. If you remain unhappy and wish to complain formally, you can do this

through the NHS complaints procedure. Details can be obtained from the hospital.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential.

Any personal information collected from you will be stored in a locked filing cabinet at the University of Nottingham.   This will be anonymous and coded. The demographic information collected will include your age and the time since you have had the operation.   This information will be used to provide information to the write up of the thesis only.

What will happen to the results of the research study?

The results of the research study will be written up as part of my Doctoral thesis with the aim of a publication in a peer reviewed journal. On completion of the interview you will be asked if you want to receive a summary of the study. You will not be identified in any report or publication.

Who is organising and funding the research?

The study is being sponsored and funded by the University of Nottingham.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well being and dignity.   This study has been reviewed and given favourable opinion by Leicestershire, Northamptonshire and Rutland 1 Research Ethics Committee.

Further information and contact details

If you require more specific information about the research project or if you would like any information or advice on whether or not you should participate in the study, please feel free to contact me on **07908 351073** or email at **lwxkjf@nottingham.ac.uk**.

Alternatively you can speak to a member of your health care team or to the Patient Advice and Liaison Service on ██████████████████████████. You could also have a look at the Cancer Research UK website at **www.cancerresearchuk.org** which has some useful information about participation in research.

Study Coordinator	**Chief Investigator**
Kimberley Fletcher	Prof. Nadina Lincoln
Institute of Work, Health and Organisations, Organisations	Institute of Work, Health and
University of Nottingham,	University of Nottingham,
Jubilee Campus,	Jubilee Campus,
Wollaton Road,	Wollaton Road,
Nottingham	Nottingham,
NG8 1BB	NG8 1BB
07908 351073	0115 9515315
lwxkjf@nottingham.ac.uk	**nadina.lincoln@nottingham.ac.uk**

Appendix C: Participant Opt-In Slip

<div align="center">

OPT-IN SLIP

The Experience of Awake Craniotomy from a Patients' Perspective

</div>

I _____

(NAME) would like to discuss the study further with the study coordinator.

My preferred method of contact is

[ ] Telephone

_____(NUMBER)

[ ] Email   _____

[ ] Post

_____

_____

_____(HOME

ADDRESS)

My preferred day or time to be contacted is

_____

Alternatively if you prefer to contact me please feel free to call me on **07908 351073**, you will have to leave a message or email me on **lwxkjf@nottingham.ac.uk** and I will get back to you as soon as possible.

Appendix D: Demographic information sheet

DEMOGRAPHIC INFORMATION

The Experience of Awake Craniotomy from a Patients' Perspective

Participant number ___

Gender: M / F

Age: ____ years

Date of awake craniotomy procedure: _____

Appendix E: Ethics approval letter

<div align="center">

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

</div>

<div align="right">

1 Standard Court

Park Row

Nottingham

NG1 6GN

Telephone: 0115 8839428

Facsimile: 0115 9123300

</div>

25 November 2009

Professor Nadina Lincoln

University of Nottingham

I-WHO, Jubilee Campus,

Wollaton Road

Nottingham

NG2 1BB

Dear Professor Lincoln

Study Title:	**The Experience of Awake Craniotomy from a Patient's Perspective**
REC reference number:	**09/H0406/111**
Protocol number:	**1**

Thank you for your letter of 18 November 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Document	Version	Date
REC application	19274/67108/1/333	
Protocol		
Investigator CV		
Evidence of insurance or indemnity		
Letter from Sponsor		
REC application	2.5	09 October 2009
Protocol	1	14 September 2009
Investigator CV	4	09 October 2009
Evidence of insurance or indemnity		28 July 2009
Letter from Sponsor		06 October 2009
Covering Letter		09 October 2009
Investigator CV	student CV	09 October 2009
Referees or other scientific critique report	c84rdi	
Investigator CV	supervisor CV	11 September 2009
Participant Consent Form	1	27 September 2009
Letter of invitation to participant	1	27 September 2009
Referees or other scientific critique report	RDI	
Questionnaire: Demographic Information	1	27 September 2009
reminder letter	1	27 October 2009
Participant Consent Form: study summery request	1	27 September 2009
Participant Information Sheet	2	18 November 2009
Participant Consent Form	Final	18 November 2009

Interview Schedules/Topic Guides	1	27 September 2009	**Conditions of**
Response to Request for Further Information		18 November 2009	**the favour**

able opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <u>http://www.rdforum.nhs.uk</u>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).
Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators

- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

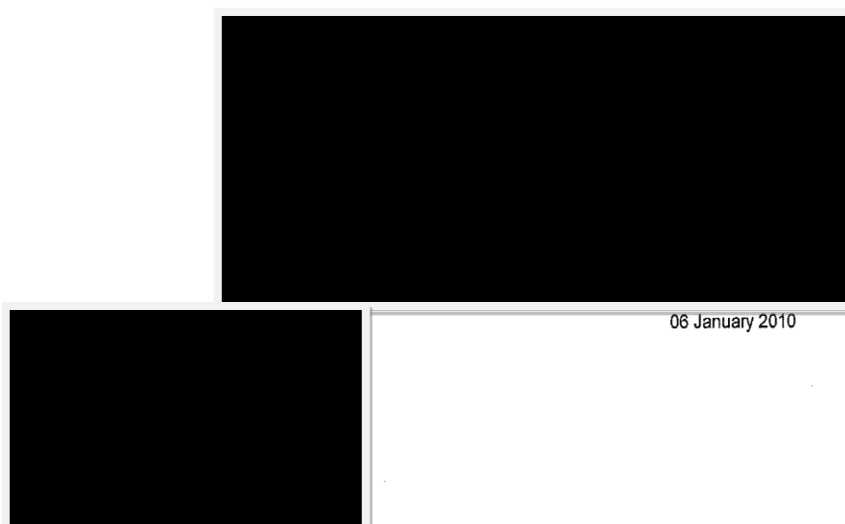| 09/H0406/111	Please quote this number on all correspondence

Yours sincerely

Dr Carl Edwards / Miss Jeannie D McKie

Chair / Committee Coordinator

Email: jeannie.mckie@nottspct.nhs.uk

Appendix F: Research and Development Approval Letter

06 January 2010

ID: 09CN002   The Experience of Awake Craniotomy from a Patient's

The R&D Department has considered the following documents:

.   Protocol, version 1.0, dated 14/09/09
.   Participant Information Sheet, version 2, dated 18/11/09
.   Participant Consent Form, version final, dated 18/11/09
.   Questionnaire, version 1, dated 27/09/09
.   Letter of Invitation to Participant, version 1, dated 27/09/09
.   OPT_IN SLIP, version 1, dated 27/09/09
.   Study Summary Request, version 1, dated 27/09/09

Your study now has R&D approval, on the understanding and provision that you will follow the conditions set out below.

Conditions of Approval

That you:

1. Accept the responsibility of Chief/Principal Investigator as defined in the current Research Governance Framework.
2. Request written approval from the R&D department for any change to the approved protocol/study documents you wish to implement
3. Ensure all study personnel, not employed by the Queens Medical Centre, University Hospital NHS Trust Nottingham or the City Hospital NHS Trust Nottingham, hold either honorary Contracts/letters of access with this Trust, before they have access to any facilities, patients, staff, their data, tissue or organs.
4. Report any Serious Adverse Event involving the Trust to the R&D department, using the Trust 'policy for research safety reporting in human subjects'. Policy available from the R&D Department.
5. Complete the R&D Research Governance interim and final reports as requested.
6. Comply with the regulatory requirements and legislation relating to: Data Protection, Trust Caldicott Guidelines, Health and Safety and the use of Human Tissue for research purposes.
7. Comply with the current Research Governance Framework, available at www.doh.gov.uk or via the R&D office or Research Governance Web-site.
8. Agree to conduct this research project in accordance with ICH Good Clinical Practice and/or the MRC Guidelines for Good Clinical Practice (as appropriate)
9. Must not start your project until you have received written approval from the relevant ethics committee.

This approval letter constitutes a favourable Site Specific Assessment (SSA) for this site.

Please note that the R&D department has a database containing study related information, and personal information about individual investigators e.g. name, address, contact details etc. This information will be managed according to the principles established in the Data Protection Act.

Yours sincerely
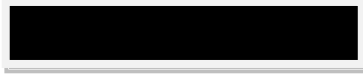
Appendix G: Ethics amendment letter

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

1 Standard Court

Park Row

Nottingham

NG1 6GN

Telephone: 0115 8839428

Facsimile: 0115 9123300

18 November 2009

Professor Nadina Lincoln

University of Nottingham

I-WHO, Jubilee Campus,

Wollaton Road

Nottingham

NG2 1BB

Dear Professor Lincoln

Study Title:	**The Experience of Awake Craniotomy from a Patient's Perspective**
REC reference number:	**09/H0406/111**
Protocol number:	**1**

The Research Ethics Committee reviewed the above application at the meeting held on 06 November 2009. Thank you for arranging for Miss██████████████████nd to discuss the study.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
REC application	19274/67108/1/333	
Protocol		

Investigator CV		
Evidence of insurance or indemnity		
Letter from Sponsor		
REC application	2.5	09 October 2009
Protocol	1	14 September 2009
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Referees or other scientific critique report	c84rdi	
Investigator CV	Supervisor CV	11 September 2009
Participant Consent Form	1	27 September 2009
Letter of invitation to participant	1	27 September 2009
Referees or other scientific critique report	RDI	
Questionnaire: Demographic Information	1	27 September 2009
reminder letter	1	27 October 2009
Participant Consent Form: study summery request	1	27 September 2009

Provisional opinion

In discussion, the Committee queried the following issues:

1. The Committee asked what the patient population is. The researcher explained that about 10 to 15 patients have had this ▮▮▮▮▮▮▮▮▮▮▮▮ since 2004. The researcher will have access to a database with the contact details and so will be able to send an invitation to them all. The researcher will know from the data base if anyone has passed away. It is a very limited population, 10 to 15 retrospective patients and 10 prospective.
2. The Committee asked for clarification of why home visits will be made. The researcher explained that the main reason for offering home visits is that these

people may have problems travelling and it is a widely spread population so some of them would have a long distance to travel if they came to the hospital.

3. The Committee asked if the reason why patients have had the operation could affect their responses and if this will be analysed. The researcher explained that the reason is not the main focus but can be recorded.

4. The Committee asked why patients with ongoing neurological problems are not excluded. The researcher explained that she has spoken to the neurosurgeons and so far no patients have come out of the operation with problems that would prevent them from participating.

5. The Committee asked about the reference to additional people not being involved in the interview. The researcher explained that if the participant wants somebody with them they can but the person will be asked not to take part in the discussion.

6. The Committee asked if you thought that this study may leads to future projects. The researcher said that it might lead to more quantitative or patient satisfaction studies.

7. The Committee asked why some of the reviewer's recommendation did not seem to have been implemented. The researcher explained that the protocol has been extensively revised since the review and so not all of the comments are still relevant.

8. The Committee asked how soon after their operation prospective patient will be contacted. The researcher explained that they are only in hospital for about 24 hours after surgery so the researcher plans to wait two to four weeks before arranging the interviews.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

1. A copy of the semi-structured interview schedule must be submitted.
2. The Committee request the following changes / amendments to the patient information sheet and consent form:
   a. A statement should be included under the heading 'What will happen to me if I take part?' explaining that if the participant wants someone else to be present this is acceptable providing that the other person does not take part in the interview or discussion.
   b. Under the heading 'Who has reviewed the study?' the name of the reviewing research ethics committee should be corrected to refer to the Leicestershire, Northamptonshire and Rutland 1 Research Ethics Committee.
   c. The consent form should make clear that data can be erased up to 48 hours after the interview as stated in the information sheet.
   d. Statement one of the consent form should be updated to refer to the new version number and date of the information sheet.

If you have any queries about the content of this letter, please contact the Co-ordinator.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates. It would help to speed up review of your response if you would email your response as well as sending a hard copy.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 18 March 2010.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Mr Steve Barrett declared that he knows the researcher but has no personal involvement with the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H0406/111	Please quote this number on all correspondence

Yours sincerely

Dr Carl Edwards / Miss Jeannie D McKie

Chair / Committee Coordinator

Email: jeannie.mckie@nottspct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1

Attendance at Committee meeting on 06 November 2009

Committee Members:

Name	Profession	Present	Notes
Miss Alison Armstrong	Consultant Orthopaedic Surgeon	Yes	
Mr John Baker	Radiation Protection Advisor and Senior	Yes	

	Lecturer (retired)		
Dr Jonathan Barratt	Senior Lecturer and Honorary Consultant Nephrologist	Yes	
Mr Steve Barrett	Research Coordinator	Yes	
Dr Martin Dennis	Consultant Vascular Surgeon	No	
Dr Carl Edwards	Director	Yes	
Dr Jayprakash Gosalakkal	Consultant Paediatric Neurologist	Yes	
Mrs Sandra Hall	Principal Lecturer in Clinical Pharmacy & Pharmacy Practice	Yes	
Mrs Bessie Hayes	Educational Psychologist (retired)	Yes	
Mr Ian Long	Solicitor	Yes	
Mr Mark McCarthy	Consultant Vascular Surgeon / Honorary Senior Lecturer	Yes	
Dr Esther Waterhouse	Consultant in Palliative Medicine	No	
Mrs Valerie Webb	Nurse	No	
Ms Rose Webster	Cardio Respiratory Education Lead	No	
Dr Iain Williamson	Senior Lecturer in Psychology	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Jeannie McKie	Committee Coordinator
Dr Kuan Huei Ng	Specialist Registrar & Observer

Appendix H: Participant follow-up letter

The Experience of Awake Craniotomy from a Patients' Perspective

Hello,

My name is Kimberley Fletcher. I have recently sent you an information pack asking if you would like to take part in a research study that wants to explore your experience of an awake craniotomy. The study will be the first in the United Kingdom to do this. The aim of the study is to help to 'give voice' to patients, with the goal of promoting an understanding for patients (past, present and future), families, healthcare teams, current and future surgeons and more broadly the NHS. The study will also form my Doctoral Thesis and will go towards my qualification as a Clinical Psychologist.

As I have not heard back from you I hope you don't mind that I have popped another copy of the information sheet, opt-in slip and stamped addressed envelope in the post. Please take the time to consider if you would like to be involved. If you would like some more information about the study or if you would like to speak with me to discuss the study further please post this back to me with your contact details and a convenient time to be contacted. I will try my best to get in touch with you at this time. Alternatively if you prefer to use the phone or email please feel free to contact me on **07908 351073** or email me on **lwxkjf@nottingham.ac.uk** and I will get back to you as soon as possible.

Again, thank you very much for your time,

Best Wishes,

Kimberley Fletcher

Trainee Clinical Psychologist

Appendix I: Participant consent form

CONSENT FORM: Final version: 18/11/09

The Experience of Awake Craniotomy from a Patients' Perspective

REC ref: 09/H0406/111   **Name of Researcher**: Kimberley Fletcher

Name of Participant: **Please initial box**

1.   I confirm that I have read and understand the information sheet version number 2 dated 18/11/09 for the above study and have had the opportunity to ask questions.

2.   I understand that my participation is voluntary and that I am free to withdraw up to 48 hours following the interview, without giving any reason, and without my medical care or legal rights being affected. I understand that should I wish to withdraw after 48 hours following the interview then the information collected cannot be erased and that this information may still be used in the project analysis.

3.   I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential.

4.   I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports.

5.   I agree to take part in the above study.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
 Name of Person taking consent   Date   Signature

_____   _____   _____
Name of Principal Investigator   Date   Signature

Appendix J: Study summary request form

STUDY SUMMARY REQUEST

The Experience of Awake Craniotomy from a Patients' Perspective

I _____(NAME)

would like to receive a summary of the study once complete.

I would like to be sent this by

Post

_____

_____

_____

_____   (Address)

Email

_____

	802	Emma: yeh probably, yeh I just didn't, no no I just	**Don't think about it**
	803	didn't, I just didn't think about it, I just thought if I	<u>**Repetition didn't think about it = emphasis on this**</u>
	804	d on't think about it then then I can't worry about	**If I don't think I can't worry**
	805	it, I don't tend to worry anyway but obviously with	*Something about self-preservation here, what*
	806	something like that I just thought well (2) (intake	*happens if she doesn't think? She doesn't have to*
	807	breath) if I had too long to dwell on it you might	*face it?*
	808	think, start thinking o god or start looking perhaps	
	809	on the internet at things n stories n all that so I	**Answers my question, too long to think would**
	810	thought no I don't want to do that nd umm what I I	**mean realisation of consequences**
	811	think that the main thing is just cuz its y'know you	
	812	go in here and you kept yourself busy I went back	**Keeping herself busy** *self-preservation strategies?*
	813	to work n didn't have enough time to sort of think	
	814	ponder it I mean and again it at the end of the day	**Going back to work, keeping herself busy**
	815	when you put your sensible head on you've gotta	<u>**Sort of think**</u>
	816	have it done, y'know if you don't wanna be	**No time to think**
	817	paralysed or (1) you want the best outcome then	
	818	it's the only sort of thing I can do really so would I	**Decision to have the awake craniotomy**
	819	suppose if they give you a choice of saying well you	**Sensible head**
	820	can be asleep or you can be awake, (2) and your	**Looking for the best outcomes**
	821	outcomes gonna be the same, I'd probably say oo	
	822	yeh I'd probably stay asleep then, but umm (2) but	**If she had the choice**
	823	then I suppose some people, I don't know whether	
	824	they get that at all, but I don't know some people	
	825	may just be curious may not want to be, y'know	**Thinking about other people's choice**
	826	may find it worse being put to sleep in an	
	827	operation I know I don't know if my brother in law	
	828	he's had a a a box in his heart, n I don't know if he	**Reflection on family members having operations**
	829	was awake for his last time, sort of went in, so I	*What is comparing it achieving?*
	830	don't know it's a bit like caesarians n things	**Comparing it to other operations**

Appendix K: A: Extract on initial noting from reflective diary

"....Sticking to Smith's guidelines seems ok. It is useful to have the framework of conceptual, linguistic and descriptive meanings. I keep referring back to them and it encourages me to think on a wider scale. It keeps me from simply looking for one aspect. I like the conceptual coding it feels like developing a formulation, although I've got to be careful or I run away with myself. I start thinking about a whole array of ideas of meaning and reference, I can't help but think why I would do that or why my friends would, It makes you realise that I think I would struggle to do anything that did not accept some kind of background knowledge and experience. Can you ever truly bracket this off. I think if I tried not to it would be impossible. That is why I like having these sheets though. They keep me from moving away from the data. When I'm writing notes I'm right next to it..."

Appendix K: B: Phase 2. Identifying emerging themes

	802	Emma: yeh probably, yeh I just didn't, no no I just	**Don't think about it**
	803	didn't, I just didn't think about it, I just thought if I	<u>**Repetition didn't think about it = emphasis on this**</u>
Not thinking about it	804	d on't think about it then then I can't worry about	**If I don't think I can't worry**
	805	it, I don't tend to worry anyway but obviously with	*Something about self-preservation here, what*
	806	something like that I just thought well (2) (intake	*happens if she doesn't think? She doesn't have to*
	807	breath) if I had too long to dwell on it you might	*face it?*
	808	think, start thinking o god or start looking perhaps	
	809	on the internet at things n stories n all that so I	**Answers my question, too long to think would**
	810	thought no I don't want to do that nd umm what I I	**mean realisation of consequences**
	811	think that the main thing is just cuz its y'know you	
	812	go in here and you kept yourself busy I went back	**Keeping herself busy** *self-preservation strategies?*
	813	to work n didn't have enough time to sort of think	
Keeping busy	814	ponder it I mean and again it at the end of the day	**Going back to work, keeping herself busy**
	815	when you put your sensible head on you've gotta	<u>**Sort of think**</u>
	816	have it done, y'know if you don't wanna be	**No time to think**
	817	paralysed or (1) you want the best outcome then	
	818	it's the only sort of thing I can do really so would I	**Decision to have the awake craniotomy**
Treatment decision	819	suppose if they give you a choice of saying well you	**Sensible head**
	820	can be asleep or you can be awake, (2) and your	**Looking for the best outcomes**
	821	outcomes gonna be the same, I'd probably say oo	
	822	yeh I'd probably stay asleep then, but umm (2) but	**If she had the choice**
	823	then I suppose some people, I don't know whether	
Comparison	824	they get that at all, but I don't know some people	
	825	may just be curious may not want to be, y'know	**Thinking about other people's choice**
	826	may find it worse being put to sleep in an	
	827	operation I know I don't know if my brother in law	
	828	he's had a a a box in his heart, n I don't know if he	**Reflection on family members having operations**
	829	was awake for his last time, sort of went in, so I	*What is comparing it achieving?*
	830	don't know it's a bit like caesarians n things	**Comparing it to other operations**

Appendix K: B: Extract on initial noting from reflective diary

"I have begun to the do the emergent themes for the first transcript. I am attempting to stick to not pulling them out during initial noting. I can see the benefit of waiting. The process doesn't get easier though. Now I am reading across two columns. It's strangely exciting as I am beginning to see the data from a new perspective. I can see what Emma said I can see my own thoughts on what she said but now I am a bit further away through their combination. It's useful to have the data next to me I can check back at what she is saying as I'm coming up with themes, just look at the quotes to ensure I'm not slipping too far away. My head keeps making leaps to psychological theory but I am trying to contain it. That isn't what this is about I need to stay with the data I need to do it so other people will say that's why she thought that"

Appendix K: C: Tally table of themes for 'Emma'

THEME	AMOUNT
Initial diagnosis	11111
Symptoms	11111
Options for treatment	1111
Decision to have operation	11111111
Operation awake task	1111
Quick succession to operation	11111111
Not thinking about it / keeping busy	1111111111
Metaphor scary ride / dentist	111
Got to have operation	111
Consideration of children	11
Feelings about operation	111111
People in the room during operation	1111
Noises during operation	111
Confirmation of diagnosis	1111
Choice for operation end	1111
What you can see in the operation	1
Operation constraint	111
Normality felt in operation	11
Appearance after operation	1111
Consideration of family	111
Back to normal follow operation	11111111
Comparison to other operations / physical conditions	111
Responsibilities aside from operation	1
Keeping occupied during operation	11111
Reflection of potential consequences	111
Searching on the internet	11
Relationship with surgeon	111111111
Get it over with	1
Feeling comfortable	11111

Appendix K: D: Theme table for 'Emma'

Super-ordinate themes	Theme inclusion
Relationship with staff and surgeon	Relationship with surgeon Feeling comfortable
Preservation of self	Distraction Keeping occupied during operation Avoidance of feelings Not thinking about it / keeping busy
Operation environment	What you can see in the operation Operation constraint Noises during operation People in the room during the operation Operation awake task Normality felt in operation
Operation reflections	Feelings about the operation Quick succession to operation Reflection of potential consequences
Information	Appearance after operation Searching on the internet
Diagnosis	Symptoms Confirmation of diagnosis Initial diagnosis
Choice / no-choice	Get it over with Options for treatment Decision to have operation Got to have operation Choice for operation end Get on with it
Responsibilities outside of the operation	Consideration of children Back to normal following operation Consideration of family

Appendix K: D: Extract from reflective diary.

"...it's strange seeing the themes all clumped together. This point didn't seem possible when I was initially noting. It is strange having an awareness of the development of each theme. I know the route of each theme or its journey and where it has developed from. I can even recall what she said for a lot of them..."

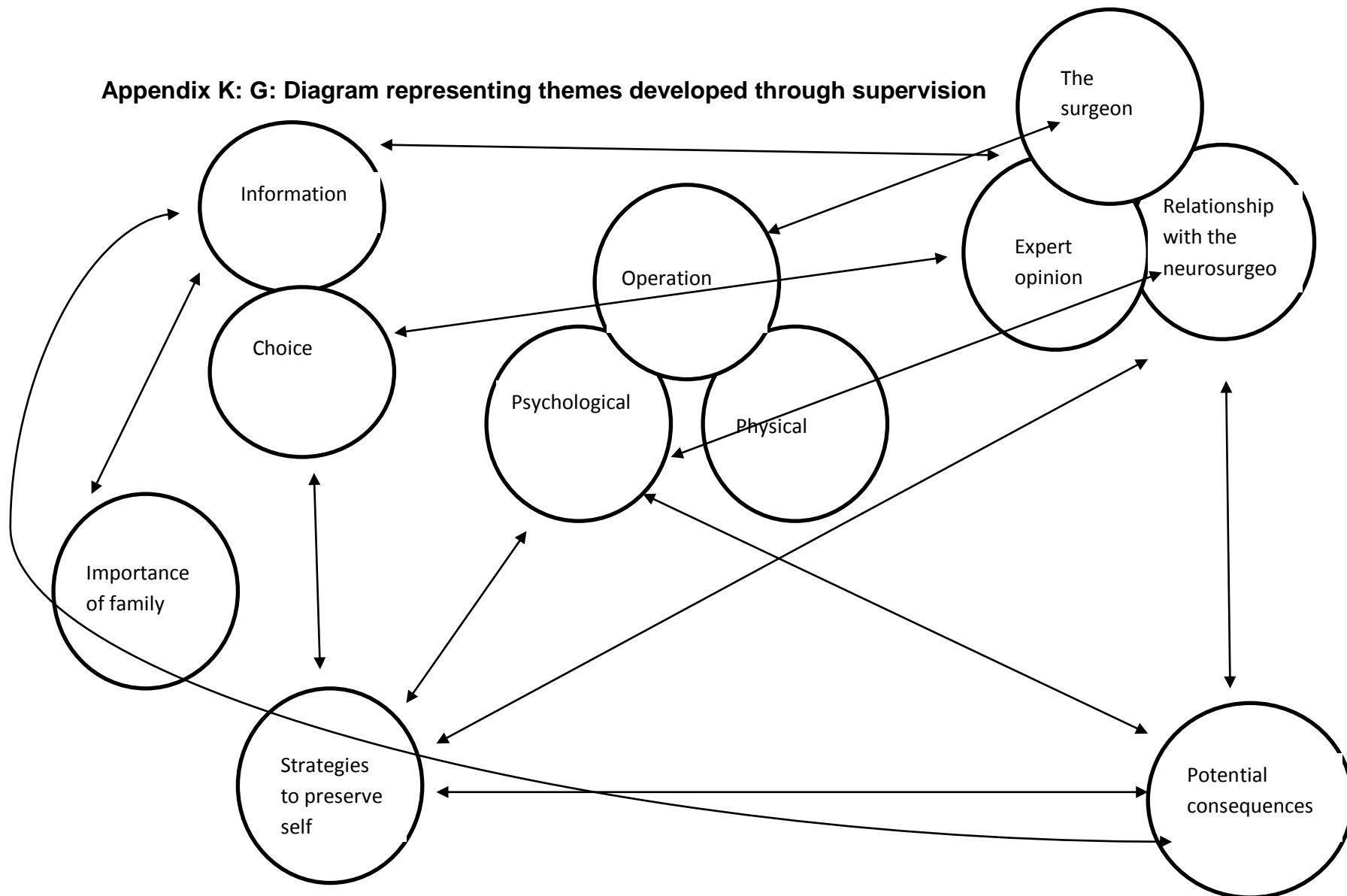**Appendix K: E: Snapshot of theme table developed for 'Emma' including quotes**

Avoidance of feelings *What would it have meant if she had to think about it.... allowed herself to feel scared /frightened?*	P3 L76	I I didn't really, to be honest, I didn't really think too much, I didn't dwell on it, or think about it too much n sort of kept myself busy	Describing picking her operation date and how quick it all came about
	P3 L88	so I just thought don't think about it, I won't dwell about it n then just get it over and done with really	Talking about husband fussing over it, before operation
	P24 L811	I think that the main thing is just cuz its y'know you go in here and you kept yourself busy I went back to work n didn't have enough time to sort of think ponder it	Talking about not wanting to look on the internet, before operation
	P24 L805	I just thought if I don't think about it then then I can't worry about it, I don't tend to worry anyway but obviously with something like that I just thought well (2) (intake breath) if I had too long to dwell on it you might think, start thinking o god o god	Following considering diagnosis, options, quick succession

Appendix K: F: Example of a recurrent theme table

1. Relationship with the neurosurgeon							
In which subtheme?	**PP1**	**PP2**	**PP3**	**PP4**	**PP5**	**PP6**	**PP7**
Relationship with the surgeon	**X**			**X**	**X**		
Expert surgeon		**X**	**X**				
Communication with professionals						**X**	
Support							**X**

Note. X = theme present for the participants

Appendix K: G: Diagram representing themes developed through supervision

The surgeon

Information

Relationship with the neurosurgeo

Expert opinion

Operation

Choice

Psychological

Physical

Importance of family

Strategies to preserve self

Potential consequences

Appendix K: G: Extract from reflective diary of generation of theme diagram

"...I went in to supervision today with an idea of my themes. Working through them with my supervisor has been useful. We have developed a diagram which I think represents turning a corner for my analysis. I'm starting to get excited about the interrelations between the themes. Considering which themes stand out and why. It is very useful to discuss this and get everything that is going around in my head on paper. I can see on the diagram that relationship with the neurosurgeon has links with most of the other themes coming through. That is interesting as it has been in my mind as an important aspect of the experience for a long time. Now I can see its' nature..."

Appendix K: H: Theme table developed through analysis write-up
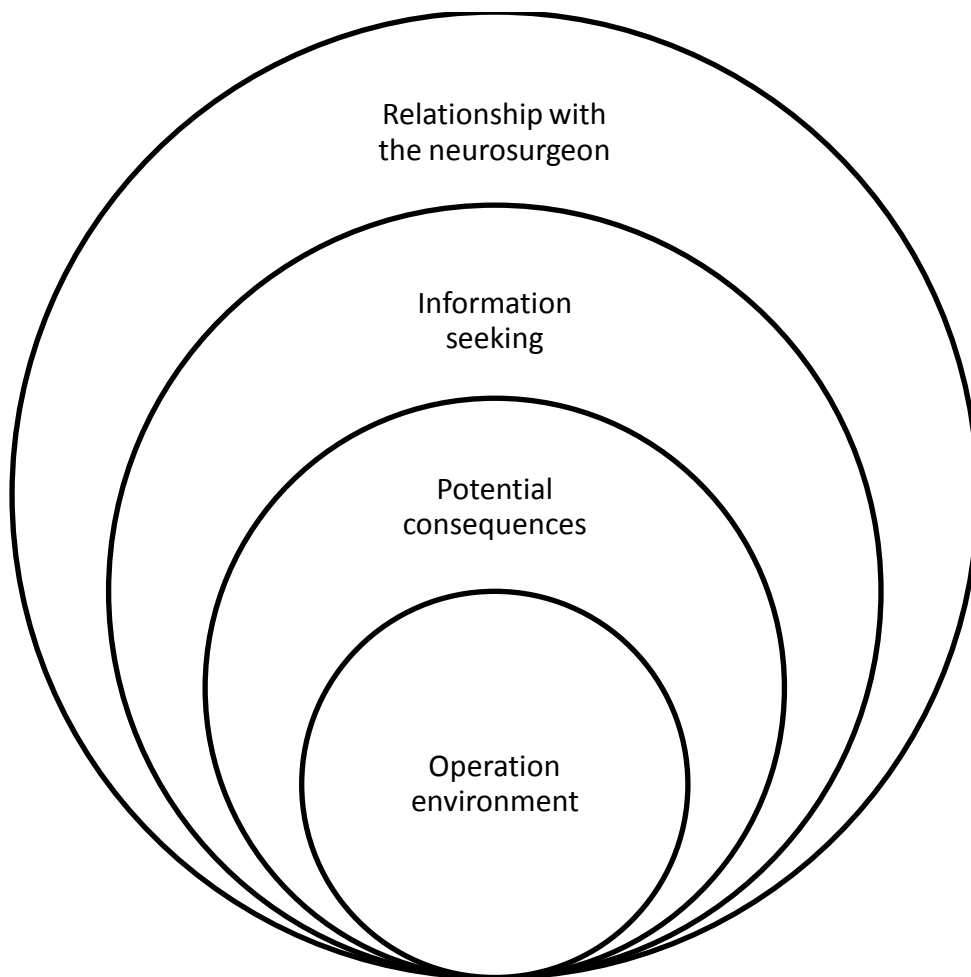
Appendix K: H: Extract from reflective diary about my initial thoughts on the relationship between themes

"... it doesn't feel right having the relationship with the neurosurgeon as an overarching theme. It feels right that it is in some way more crucial to the other themes but having it as an overarching theme is not quite right. I can't put my finger on it but this theme is more than overarching, it didn't follow other themes it is within them. It is underneath them...."

Appendix L: Extract from reflective diary after an interview

"... I always feel so exhausted when I come out of interviews. I feel that that went well. She spoke a lot and had a lot to say which was good. I felt we really got in to a flow throughout the interview. I barely had to say anything. I felt sorry for her this time. I don't have that very often and she certainly didn't induce it but she was my age. She talked with such strength. I couldn't help but let my mind drift in to thinking would I be like that? I had a lot of respect for her words, perhaps it is because she is a similar age to me, I couldn't imagine myself in her position. It was a very intense interview..."