

## Coping with an awake brain tumor resection in patients and their primary contacts: A qualitative study

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### Abstract

**Background.** The diagnosis and awake removal of a brain tumor is a major life event. A better understanding of the needs of this group of patients and their primary contacts in the perioperative trajectory can further improve care.

**Methods.** Adult patients who underwent an awake craniotomy (AC) in the Erasmus MC, the Netherlands and their primary contacts were interviewed 1–2 weeks prior to surgery and 2–4 weeks after surgery. Semi-structured interviews on the impact of the diagnosis on their lives and coping mechanisms with the AC procedure were conducted. Interview transcripts were analyzed in accordance with the principles of grounded theory.

**Results.** Twenty-one patients and 19 primary contacts were interviewed at least once during this period. Analyses and coding of the transcripts resulted in a conceptual model, distinguishing coping with the disease and coping with specific procedures of AC. In general, participants tended to rely on their pre-existing ways of coping. Situation-specific coping mostly refers to perceiving control, and related to that, trust in the medical team.

**Conclusions.** Patients with a brain tumor and their primary contacts perceive coping with the AC procedure as a part of coping with the disease. Although the procedure may be perceived as stressful, at the same time it offers hope and prospect. In coping with the specifics of the AC procedure, we found that feeling in control and as an extension of that, trust in the AC team were key aspects.

### Key Points

- Awake craniotomy is perceived as part of a larger whole (being diagnosed with brain cancer).
- Patients and relatives tend to rely on their pre-existing ways of coping.
- Situation specific coping consists of perceiving control, and trust in the team.

Awake craniotomy (AC) is an important first step in the treatment of patients with tumors within or adjacent to eloquent brain regions. Despite its curative intent, it has been associated with psychological strain and increased levels of anxiety, depression, and PTSD.<sup>1–4</sup> This is especially so as patients with brain tumors are more likely to experience mental health problems compared to patients with other types of cancer.<sup>5</sup> Recent reviews, however, concluded that although the psychiatric impact of AC should not be underestimated, in experienced

hands, AC does not cause an increase in stress, anxiety, and depression<sup>2</sup> and overall patient perception of and satisfaction with AC is high.<sup>4,6–8</sup> The caveat “in good hands” is important here. First of all because one would want the operation to have the best possible outcomes, and second because the trust patients put in their AC OR team seems crucial for the procedure’s course and results.<sup>3,9,10</sup> The patient-professional relationship is not the only factor influencing perioperative outcomes, as these are also influenced by the way patients participate in

## Importance of the Study

This study addresses how patients and their relatives cope with the situation of undergoing awake brain tumor resection, both before and after surgery. As such, this study contributes to the development of a consensus psychiatric assessment tool for patients undergoing

awake brain tumor surgery, as was recently proposed by other authors in the field. Given our results, a notion of feeling in control (vs helplessness), and questions that address the bond with and trust in the awake craniotomy team should be part of such a general measure.

and cope with the AC-procedure.<sup>11</sup> Coping refers to how one handles a stressful situation. Coping with AC has been studied to some extent.<sup>2</sup> These studies tend to focus on specific actions to help people prepare for AC. Examples include visiting the OR (operating room) beforehand and practicing postures,<sup>12–14</sup> which in short can be defined as exposure techniques. Such exposure may serve both practical and emotional preparation, as exposure may help to adjust expectations and consequently reduce stress.<sup>15</sup> Other preparatory actions to help improve coping during AC include instruction of stress-management techniques such as breathing exercises.<sup>13</sup> A critical note to these valuable studies is that they seem to depart from a professional perspective, describing what has been done to support patients. Less is known from a patient's perspective. For instance, social support from the family is also relevant for preparing patients and accommodating them before and after AC. The study by Bala et al. for instance (2022) found that the support of family and friends is helpful in preparing for the procedure.<sup>9</sup> Another factor related to coping in patients with cancer and their caregivers is religion and spirituality. Compared to some other types of cancer, patients with brain cancer may be extra vulnerable to religious and spiritual needs due to a high mortality risk and risk of loss of personality.<sup>16</sup> Still, not much work has been done in this field, and in addition, some of the studies done lack preoperative psychological data.<sup>1</sup> This is a shortcoming because it does not allow one to include the possible effects of how people perceive and deal with undergoing AC beforehand. Therefore, the purpose of this study is to learn how patients and their primary contacts cope with the AC procedure, to better understand (1) how patients' coping may develop over time, (2) how their primary contacts cope with the AC procedure over time, and (3) the specific role of (a) social support and (b) religion and spirituality in coping with the AC procedure.

## Methods

### Patients

Adult patients who underwent an AC for brain tumor resection in the Erasmus MC between February 2019 and November 2020, the Netherlands and their primary contacts were interviewed twice: 1–2 weeks prior to surgery and 2–4 weeks after surgery (see [Supplementary Appendix](#) for interview guides). Awake craniotomies have been performed in Rotterdam since 2002. Since then, over 500 operations have been done, with current yearly numbers of

around 15 patients/year. Eligibility for the awake procedure is first checked by the neurosurgeon, who addresses the risk of functional damage by the tumor removal. The anesthesiologist evaluates whether an awake procedure can be safely performed. In general, the ability to communicate with the patient is the most important factor. We also include patients with glioblastoma and patients with low KPS, as long as cognitive function is maintained at a level that allows safe guidance through the procedure. Patients in this study were awake before positioning, asleep before craniotomy, awake before resection, and asleep before closure.<sup>17</sup> All patients eligible for this procedure could be included in this study. There were no specific exclusion criteria. Patients were sampled consecutively, that is all patients visiting the outpatient clinic within a certain time frame were invited to participate in this study.

### Procedures

Patients were invited by their medical doctor and handed the patient information. One week later, they were called by the researcher, to ask whether they were interested to participate. Via the patients, we asked for permission to also interview their primary contact. After informed consent was given, interviews were performed by Tv.A. (anesthesiologist in training) under the supervision of L.K. (healthcare psychologist). To minimize the study burden on participants, telephone interviews were conducted. Interviews were recorded using an audio recorder and transcribed thereafter. This study was approved by the medical ethics committee of the Erasmus MC (MEC-2018-1721).

### Analysis

The study design was based on a grounded theory approach.<sup>18,19</sup> Interview transcripts were first coded by Tv.A. (anesthesiologist in training, but not part of the AC team) and Mv.H. (medical student), going through the coding phases of open, axial, and selective coding, using NVIVO (version 10.5), and regular meetings with together with L.K. (healthcare psychologist) were held to discuss findings. In doing so, the coders compared their coding frameworks on all levels of coding and discussed differences until a consensus was reached. Assessing the same texts by 3 different people with differences in professional background, age, gender, and expertise can be referred to as triangulation, applied to counteract tunnel vision in interpreting the data. Analysis continued until a sufficient level of "saturation" had been reached—in this study

**Table 1.** Participant Characteristics

Nr.	M/F	Age	Patient	WHO grade	Complication	Caregiver	
			Type of tumor			Relation to patient	M/F
1	M	58	Glioblastoma, IDHwt	4	None	partner	F
2	F	43	diffuse astrocytoma, IDH mutant	2	Wound infection	Partner	M
3	M	32	oligodendroglioma, IDH mutant, and 1p/19q codeleted	2	None	Partner	F
4	M	36	diffuse astrocytoma, IDH mutated	2	None	Partner	F
5	F	32	diffuse astrocytoma, IDH mutated	2	None	Parent	F
6	F	51	minigemistocytoma, IDHwt, TERT mutation, PTEN mutation, NF1 mutation	2	None	Parent	F
7	M	65	Glioblastoma, IDHwt	4	None	Partner	F
8	F	32	Anaplastic astrocytoma, IDH mutated	3	None	Partner	M
9	M	33	oligodendroglioma, IDH mutated	2	None	Partner	F
10	M	38	diffuse astrocytoma, IDH mutated	2	None	partner	F
11	M	31	Oligodendroglioma, IDH mutant and 1p/19q codeleted	2	None	partner	F
12	M	46	Oligodendroglioma, IDH mutant and 1p/19q codeleted	2	None	Partner	F
13	M	25	Ganglioglioma	1	None	Parent	F
14	M	40	Astrocytoma, IDH mutated	4	None	Partner	F
15	M	35	Astrocytoma, IDH mutated	2	Subdural hygroma	Partner	F
16	M	45	Anaplastic Oligodendroglioma, IDH mutated, 1p/19q codeleted	3	None	Partner	F
17	M	38	Anaplastic astrocytoma, IDH mutated	3	None	Partner	F
18	F	43	Oligodendroglioma, IDH mutated, 1p/19q codeleted	2	None	Sibling	F
19	M	37	Anaplastic Oligodendroglioma, IDH mutated, 1p/19q codeletion	3	None	Partner	F
20	M	48	Melanoma (metastasis)	-	None	partner	F
21	F	30	Diffuse astrocytoma, IDH mutant	2	None	Parent	F

defined as saturation on the level of data collection (the degree to which new data repeat what was expressed in previous data) and analysis (the emergence of new codes or themes).<sup>20</sup> Furthermore, findings were discussed in the larger research team including a senior anesthetist (M.K.) and psychologist (J.B.). After careful consideration and adjustments, the final conceptual model was agreed upon by all team members. This model can be perceived as a summary of the main result of this specific study and is meant as a framework that enables explaining and summarizing the core findings in a couple of sentences.

## Results

### Participants

All eligible patients and their primary contacts in this timeframe were invited for study participation. Of those, all consented. Twenty-one patients and their primary contacts were interviewed before surgery. Two primary contacts declined participation after surgery, stating logistical reasons (lack of time). [Table 1](#) provides an overview of patient and primary contacts' characteristics.

### Results From the Interviews

Analyses of the transcripts resulted in a conceptual model of how patients and their primary contacts cope with awake brain surgery ([Figure 1](#)).

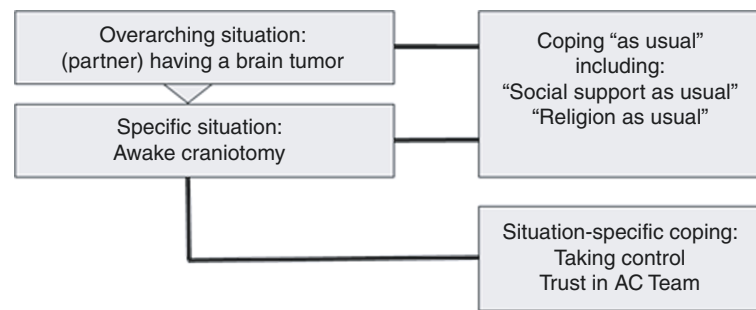
### Situational Aspects

The left side of the model separates the situation of undergoing an AC-procedure from the broader or more general situation of having a brain tumor; wherein the first is clearly perceived as a (life) threat, and the latter as a situation or opportunity for improvement.

In parallel to the above, disease-specific and procedure-specific coping could be discerned.

### Disease-Specific Coping

Disease-specific coping is best summarized as "coping as usual," meaning that respondents (both patients and their primary contacts) tended to rely on pre-existent coping strategies. Often applied strategies included making use of social support and relying on one's life view, which could be religion-inspired.



**Figure 1.** Conceptual model of how patients and their partners cope with awake brain surgery.

For example, social support was described as:

*"It is mainly that we have done it with the four of us, so with the family" (female, partner)*

*"I just had a lot of support, so to speak, from all kinds of people from all kinds of groups in which I also function and they were present at an extra energetic level, so to speak, and offered support." (female, patient)*

On the other hand, not making use of social support was also mentioned. In case respondents had a preference to rely on themselves and not reach out that much in general, then this was also the position they took in this specific situation of dealing with the brain tumor:

*"I have little or no family myself. We have also deliberately kept people at a distance. ... We are a couple that is always together. We have no children of our own, deliberately so. The support we received was very limited, but that was our need." (female, partner).*

Examples of coping by relying on one's philosophy of life were:

*"I surrendered her into the hands of doctors, but also into the hands of God. And I asked that He would arrange and equip the hands of the doctors. Then it becomes more difficult job. And that is also double, because then, you hope for an even greater miracle than you have already received. And I have to deal with that." (female, mother of patient)*

*"I was not religious at all or brought up with a faith or anything like that. And well, I had, I never really did much with that. Actually nothing. And well, I can't say that anything has really changed." (female, patient)*

Next to the coping styles named above, many other coping styles were applied, for example, avoidance, seeking distraction, and relativism. Again here, applying these strategies did not come across as something respondents did for the first time, but more as "their way of dealing with difficulties in life":

*"Well look, let me put it this way. The emotion is not so much there when you're obviously busy with other things. If I would naturally sit on the couch all*

*day with a book or read all day or I don't know or sit still - I'm not a fan of sitting still. I'm someone who likes to be busy, so to speak. So, I check my mail, I call people, I talk to people, to staff. And that's just a lot of distraction so to speak. So basically, I just want to keep functioning even before the surgery, because I don't really feel lousy." (male, patient)*

*"I'm someone who tries to be reasonably optimistic. So I was able to put things into perspective and think, well, it won't be so bad. (male, patient)"*

Both patients and their primary contacts tended to rely on already existing coping strategies. There were differences between patients and their primary contacts, related to differences in role functioning, with one being the patient, and the other (most often the partner) caregiver.

### Procedure-Specific Coping

Procedure-specific coping included 2 main strategies: striving for control and trust in the professional team. Aiming for a sense of control seemed to function to grab hold, to prevent getting overwhelmed by emotions until one feels completely powerless. For instance, one female patient said:

*"In any case, I have confidence in it. That they are very skilled specialists and I also have confidence in myself, that I know what to do. It is an awake operation, so I can indicate what I feel."*

Quotes illustrating the importance of trust in the team were:

*"I think there have already been 500 or so operations of that kind, and if you also see the experience that is there, then you confide" (female, patient)*

*"I think she's in very good hands, first of all. So, I am really confident that she can be helped here in the best way for this condition." (partner, male)*

For both patients and their primary contacts, trust in the team was important in coping. With regard to taking or handing over control, one may say that primary contacts were in an even more dependent position (both of the team and of the patient), which may provide an explanation for the finding that many primary contacts named "receiving

the call that the operation went well" as a good and meaningful experience.

## Discussion

The main outcome of this study is that patients and their primary contacts in the unusual situation of an awake brain tumor resection apply the type of coping that they usually turn to in stressful situations. This means, that if for instance one tends to seek distraction as a means to cope with difficult situations, he/she is likely to also apply this strategy to cope with having a brain tumor or your loved one having a brain tumor. In this respect, it is important to take coping functions into account,<sup>21</sup> that is, "coping" is not to be seen as an end in itself, but as a means to an end. Functions of coping for instance can be to reduce harmful external conditions, to maintain a positive self-image, or to maintain a certain emotional equilibrium.<sup>22</sup> Although this study focused on coping with the AC procedure, many respondents spontaneously or perhaps automatically redefined this as a sub-topic of dealing with having a brain tumor. This is in line with previous findings, wherein patients also emphasized that they were more afraid of the disease than awake surgery.<sup>8</sup> In general, the disease in itself is merely perceived as a threat (to life, health, family life, work, and income), whereas the AC procedure itself is perceived as something good. It brings hope for the improvement of one's health and situation. This does not mean that the AC procedure is easy and may not cause any stress, but overall, this distinction between disease and cure should be kept in mind. Also, the link with coping pioneers Lazarus and Folkman's work<sup>23</sup> urges here: following their transactional model of coping,<sup>23</sup> a particular event is first evaluated in terms of threat, and after that in terms of how one estimates his/her resources to cope. So, although the cancer is perceived as a (life)threat, the AC procedure -put in perspective- is not. This difference translates into differences in coping, in which specific features for coping with the AC procedure stand out. By participating in surgery one takes control, as "at least something can be done." This is especially true for the situation of AC, as we found that the fact that patients actively participate during this procedure contributes to feelings of control. Other studies also show that feeling in control is what helps patients most to come through surgery and reduce stress.<sup>9</sup> It has even been argued that AC is even less stressful than general anesthesia,<sup>24,25</sup> because patients experience some sort of control and a positive sense of responsibility.<sup>26</sup> In fact, the most important for them in this study was to control the situation. It is this balance between being active/in control and being handed down that explains why the relationship with the AC team is of utmost importance. One might even say that the feeling of being in control is transferred to the members of the AC team. Other studies also underline the importance of a good therapeutic relationship, based on openness and trust.<sup>3,9</sup> In addition, the feeling of being in control can be strengthened by shifting their focus from "being in such a position and thinking of what may go wrong" to the cognitive tasks that need to be performed during the procedure. This concept of "task

concentration" is already applied in various types of psychological treatment, especially when a fear component is present.<sup>27</sup> In this paradigm, patients are learned to shift attention from the self (eg, "I am unable to do this") or surroundings (eg, "They must think I am stupid") to the tasks that are to be performed (eg, giving a presentation). Previous studies indeed found that patients prefer to think about the tasks they would have to face (instead of undergoing surgery).<sup>9,26</sup> The findings of these and our studies underline the importance of perceived control. "Control" is a key concept in the classical self-regulation theory that proposes feedback loops to self-regulate behavior.<sup>28</sup> Both taking control (by a strong focus on the cognitive tasks inherent to the AC procedure) and handing over control (by means of trust) may help patients get through to procedure properly.

## Strengths and Weaknesses

This is one of the first studies to include primary contacts of patients undergoing AC, in a prospective design. This has enabled us to get a more complete picture of their coping in this situation. The design of an open qualitative approach, by not focusing on a specific coping style, mode, or strategy is also an advantage of this study. If we had predefined this by starting from a specific coping model or questionnaire, we may have missed the relevance of the situation at stake. One exception to this design, which may be viewed as a weakness is that the topic list did include one specific question about religion, which in some way is a deviation from the otherwise open, bottom-up way of research. There are many coping theories or models, partly overlapping and each with their own emphasis. A common factor of contemporary models is that they tend to view coping as a multi-dimensional and complex process, influenced by a variety of factors.<sup>21</sup> Studying coping with the AC procedure on the basis of one of these new models, would have required a different study design, in which one would start with a specific theory in advance. Although we choose not to do so in this study, it would be interesting for future research. A particular theory of interest is acceptance and commitment theory because dealing with brain tumor(s) and its treatment asks for a (continuous) process of adaptation referred to as psychological flexibility.<sup>29</sup> Another advantage of taking this theory as a starting point, would be its strong connection with therapeutic possibilities, which could be a solution for those patients or their primary contacts who cannot cope with the situation on their own. The main weakness of this study is that although originally we aimed to start from a grounded theory approach, with hindsight we feel that the data collection process, the richness of the data, and the way we have conceptualized saturation, may better be described as thematic analysis, for instance as proposed by Braun and Clarke.<sup>30</sup> Furthermore, reflecting on team members' roles, especially of the interviewer, it comes to mind that despite understanding the study design rationale, at times a more straightforward and structured medical-formal approach was adopted, which might have led to missing opportunities for further deepening of data. This point relates to the trustworthiness of the work, in particular to its



credibility.<sup>31</sup> On the other hand, to promote credibility (and confirmability), we applied triangulation from multiple personal and professional perspectives during data analysis. To further strengthen credibility, we applied multiple measurements per respondent (before-after), and engaged in member checking during the interviews. To ensure dependability, we had 2 researchers coding the data, with multiple points for cross-checking and discussion during the process. Finally, to enhance transferability, we used consecutive sampling, allowing for a representative study sample.

### Clinical Implications

Our findings might contribute to the development of a robust consensus psychiatric assessment tool for patients undergoing AC, as recently suggested.<sup>2</sup> Given our results, and those of other studies in the field,<sup>3,6,8–10,26</sup> a notion of feeling in control (vs helplessness), and questions that address the bond with and trust in the AC team should be part of such general measure. Furthermore, emphasis on the AC team-patient (system) relationship is important, and effort should be made to (continue) investing in interventions to enhance this relationship. Given that this relationship takes shape through both non-verbal and verbal communication, further research may be done in the field of positive use of language, which already has been shown to lead to decreased pain, anxiety use of analgesics.<sup>32,33</sup> A way to further validate the model would be member checking, most elegantly in a structured way such as including those patients and their primary contacts who participated in the study.<sup>34</sup> In addition, it would be worthwhile to present the model at international professional meetings for neuro-oncologists, surgeons, and anesthetists.

### Conclusion

Patients with a brain tumor and their primary contacts perceive coping with the AC procedure as a part of coping with the disease. Although the procedure may be perceived as stressful, at the same time it offers hope and prospect. How patients and their primary contacts deal with this, aligns with how they normally tend to handle stress-evoking situations. In coping with the specifics of the AC procedure, we found that feeling in control and as an extension of that trust in the AC team were key aspects.

### Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (<https://academic.oup.com/nop/>).

### Keywords

awake craniotomy | coping | patients and partners | psychology | qualitative research

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### Conflict of interest statement

None declared.

### Authorship statement

L.K.: conceptualization, analysis, writing the first draft; Tv.A.: data collection, analysis, writing; Mv.H.: analysis; J.S.: supervising; J.J.B.: analysis, supervising; M.K.: conceptualization, analysis, supervising.

### Data availability

Pseudonymized data will be made available upon reasonable request.

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