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Pain management experiences among hospitalized post-craniotomy brain tumor patients

Rebecca E. Foust Winton, PhD, RN, **Claire B. Draucker, PhD, RN, FAAN**, **Diane Von Ah, PhD, RN, FAAN**
Department of Community and Health Systems, Indiana University School of Nursing, Indianapolis, Indiana, United States of America

Abstract

Background: Brain tumors account for the majority of central nervous system tumors, and most are removed by craniotomies. Many post-craniotomy patients experience moderate or severe pain after surgery, but patient perspectives on their experiences with pain management in the hospital have not been well described.

Objective: To describe how patients who have undergone a craniotomy for brain tumor removal experience pain management while hospitalized.

Methods: Qualitative Descriptive methods using semi-structured interviews were conducted with patients on a neurological step-down unit in an urban teaching hospital in the Midwest United States. Interviews focused on how patients experienced post-craniotomy pain and how it was managed. Narratives were analyzed with standard content analytic procedures.

Results: Twenty-seven participants (median age 58.5 years, IQR 26–41, range 21 to 83 years) were interviewed. The majority were Caucasian (n= 25), female (n = 15), and had an anterior craniotomy (n=25) with sedation (n= 17). Their pain experiences varied on two dimensions: salience of pain during recovery and complexity of pain management. Based on these dimensions, three distinct types of pain management experiences were identified: 1) pain-as-non-salient, routine pain management experience; 2) pain-as-salient, routine pain management experience; and 3) pain-as-salient, complex pain management experience.

Conclusions: Many post-craniotomy patients experience their pain as tolerable and/or pain management as satisfying and effective, others experience pain and pain management as challenging.

Implications for Practice: Clinicians should be attuned to needs of patients with complex pain management experiences and should incorporate good patient/clinician communication.

Keywords

brain tumor; pain; post-operative; qualitative; inpatient

Correspondence: Rebecca E. Foust Winton, PhD, RN, Department of Community and Health Systems, Indiana University School of Nursing, 600 Barnhill Drive, NU400, Indianapolis, Indiana 46202; 317-661-0469 (phone) / 913-689-7555 (fax) (refoust@iu.edu).

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Introduction

Approximately 23,800 persons were diagnosed with a brain tumor in the United States in 2017,[1,2] and a large majority of these persons underwent a craniotomy for tumor removal.[2] Post-craniotomy pain is a significant clinical concern for some patients who undergo craniotomies. Post-craniotomy pain is caused by the incision of the skin and the retraction and reflection of the muscles of the scalp, which is profusely innervated by large and small diameter nerve fibers.[3,4] Post-craniotomy pain is primarily superficial in origin and often involves the scalp, muscles, and soft tissue of the head, although manipulation of the dura mater covering the brain can also trigger painful sensations.[5] The nature of the pain experienced by post-craniotomy patients is related to the surgical site, with incisions in the subtemporal or suboccipital region producing higher incidences of pain.[5]

While the postoperative period can extend from the end of surgery to when normal functioning has been restored,[6] much of the emphasis on post-craniotomy pain has focused on the time between the end of surgery and discharge from the hospital. Although the percentage of post-craniotomy patients who experience pain within the first two days after surgery is found to be as high as 60–96%, despite the use of analgesics, research suggests that clinicians may undertreat this pain as they mistakenly believe that craniotomies are less painful than other types of surgery due to lack of innervation in the brain.[5,7–8] In addition, clinicians may be reluctant to prescribe opioids for post-craniotomy pain because these medications can cause decreased or altered levels of consciousness, thereby masking important neurological changes, or because they can cause respiratory depression leading to increased intracranial pressure and compromised cerebral circulation.[4] Moreover, nausea and vomiting resulting from analgesic administration can increase blood pressure and contribute to an increased risk of aspiration.[9,10] Effective management of post-craniotomy pain may also be compromised because few non-pharmacologic strategies for pain management have been developed and tested in this population.[11,12]

Pain management for craniotomy patients following surgery typically includes the use of opioids,[13–16] alpha-2 adrenergic agonists[12] such as dexmedetomidine,[13, 15, 17–18] and adjuvant pain medications.[19–20] The addition of atypical analgesics, such as COX-2 inhibitors, to hospitalized patients' pain regimens may decrease side effects and increase earlier mobilization, thereby reducing hospital stay and associated costs.[9, 21–22] A few studies have examined nonpharmacological interventions for pain management for craniotomy patients. For example, the use of scalp nerve block during surgery has been shown to decrease the need for additional analgesia after surgery and increase the time between the end of surgery and post-operative analgesic administration.[13–26] Techniques such as wound infiltration have also been shown to result in temporary decreases in pain after surgery.[27]

Complementary interventions considered to be safe for pain management by the American Pain Society, such as massage and cold or heat therapy, have not been examined in the post-craniotomy pain population.[22] Moreover, while a number of other complementary and self-management interventions, such as acupuncture, yoga, music therapy, guided imagery, and progressive muscle relaxation, have been used to manage generalized cancer pain, the effectiveness of these interventions in persons with post-craniotomy pain has not been studied.[28–37]

Untreated or undertreated pain while hospitalized can negatively affect a number of health outcomes. First, unrelieved pain following surgery may cause permanent neurological changes leading to the development of persistent neuropathic pain.[38–39] In addition, unrelieved pain may cause agitation and sympathetic stimulation resulting in increased blood pressure and swelling.[22] Moreover, acute post-craniotomy pain in brain tumor patients is associated with greater healthcare burden including longer lengths of stay and higher costs of hospitalization,[12] delayed mobilization,[12] higher rates of disability, and poor perceived quality of life due to increased anxiety and depression.[8, 39–41]

Despite calls for the development of better strategies to manage post-craniotomy pain, little is known about patient perspectives on pain management following surgery. Initiatives to improve pain management in this population would be enhanced with a better understanding of the pain management experience as described by post-craniotomy patients in their own words. The purpose of this study was to describe how persons who have undergone a craniotomy for excision and removal of a brain tumor experience pain management while hospitalized.

Methods

Qualitative Description (QD) methods, as described by Sandelowski,[42–43] guided this research. QD is the method of choice when the goal of the research is to summarize the experiences of a group in common, everyday terms. In QD, purposive sampling is often used to target persons who have experienced the phenomenon of interest and can articulate their experiences, and semi-structured interviews are typically used to generate focused information about participants' experiences.[42–43] When using QD, researchers use low inference analytic strategies such as standard content analysis to summarize data rather than generating abstract concepts from the data set.[42–43] These strategies allow researchers to make interpretations that are close to the data or "data-near."[43] The outcome of QD is a straightforward summary of the data presented in such a way that it answers important pragmatic practice questions. Because we aimed to provide a straightforward description of patients' pain management experiences following craniotomy, QD methods were most applicable to this study.

The study methods are reported according to the COnsolidated Criteria for REporting Qualitative Research (COREQ).[44] To ensure rigor, the primary investigator kept a detailed audit trail to chronicle all analytic and methodological decisions that was reviewed regularly by the other team members. Other strategies to enhance the trustworthiness of the findings are described throughout the report.

Setting

Data were collected from February 2016 through December 2016 at an urban teaching hospital, where an average of 900 craniotomies for the treatment of brain tumor are performed annually. The neurosurgical practice of the hospital draws patients from throughout the Midwestern United States. The study was conducted on a 23-bed neurosurgical step-down unit, where patients who have undergone procedures for neurological injuries and illnesses including craniotomies are treated. Patients transferred to this unit are clinically stable with acute care needs that prevent them from being transferred to a medical-surgical acute care unit. Standard post-operative pain medication order sets, which include a variety of recommended oral and intravenous analgesics, are used on the step-down unit.

Inclusion and Exclusion Criteria

Patients who had a craniotomy for the excision and removal of a primary brain tumor within the prior two weeks were recruited for the study. Although patients typically experience post-craniotomy pain in the first two days after surgery,[7] we selected a two-week time period to capture patients who may have experienced lingering pain while still hospitalized. Other eligibility criteria including being age 21 years and older and speaking English fluently. Patients who were clinical unstable, actively psychotic, and or who had hearing, speech, or cognitive deficits that would interfere with full study participation were excluded.

While there are no specific guidelines to determine the exact sample size in qualitative studies, methodologists indicate that approximately 20 to 50 participants are typical in QD studies.[45–46] The final sample size is determined by the number of interviews needed to obtain sufficient information to comprehensively address the study purpose. Because we had a single and straightforward research aim, we estimated that between 20 and 30 participants would supply ample data to accomplish the aim.

Recruitment

Institutional review board approval was obtained from the investigators’ university (protocol number: 1503204788) and a waiver of authorization to use protected health information for study recruitment was obtained from the hospital. During each week of recruitment, the medical records of consecutive patients who had been hospitalized for the treatment of primary brain tumor were reviewed by the clinical nurse specialist (CNS) on the unit to determine eligibility. The CNS generated a list of eligible patients and approached them to obtain their verbal consent to be contacted by the primary investigator (first author), a female doctoral candidate with experience in acute care nursing, to discuss the study. The primary investigator approached and greeted potential participants, and using a standard script, described the study, confirmed eligibility, and discussed the study requirements. Written informed consent for the interview and review of medical records was obtained from patients who agreed to participate. Participants were informed that their participation was voluntary and that they could choose to withdraw from the study at any time.

Data Collection

In order to fully describe the sample, the following data were collected by the primary investigator from the participants’ medical records: (1) length of hospital stay; (2) participant age, gender, body mass index, and race/ ethnic background; (3) tumor type, grade, and location; (4) surgical approach, length of time, and head positioning; (5) documented pain ratings; (6) Glasgow Coma Scale ratings; (7) analgesics prescribed, dosages, and number of doses administered; (8) steroids prescribed, dosages, and number of doses administered; (9) prior pain history; and (10) prior opioid use.

To ensure reflexivity, the primary investigator explored personal biases and assumptions with the senior researchers (second and third authors) prior to conducting interviews and throughout the research. Participants had no prior relationship with the primary investigator, who informed them of the purpose of the study during the recruitment process. Each participant was interviewed once. All interviews were conducted in the participants' hospital rooms and were audio-recorded with a digital recorder. The interviews included questions about (a) how the participants described their pain since surgery, (b) how they dealt with their pain, and (c) how their clinicians managed their pain. Prompts were used to obtain robust descriptions of their pain management experiences. For example, whenever possible, the participants were asked to describe specific interactions with clinicians related to pain management. A few family members were present for the interviews and, in some instances, their comments were recorded. These comments were redacted from the transcripts as family members had not consented to participate in the study. There were not notable differences in the quality of the interviews or type of information shared depending on whether family members were present or not.

The interviews were audio-recorded and transcribed by a professional transcriptionist. Field notes were made during the interviews. The transcriptions were compared to the audio recordings by the primary investigator to verify for accuracy. Interviews were conducted until the research team determined that enough information had been obtained to produce a robust description of a variety of ways in which post-craniotomy pain was experienced and pain management occurred and a straightforward summary that had implications for clinical practice could be written.

Data Analysis

Demographic and medical data were described with frequency counts and percentages. Pain intensity ratings and Glasgow Coma Scale ratings were each summarized and averaged for each inpatient day. For the qualitative analysis, the principal investigator and two senior nurse researchers, one with expertise in qualitative methods (second author) and one with expertise in oncology (third author), comprised the analysis team. The data were analyzed in four stages using standard content analytic procedures as described by Miles, Huberman, and Saldaña.[47]

First, all team members read through the transcripts several times to obtain a thorough understanding of the participants' overall pain management experiences. Second, the primary investigator highlighted and extracted text units (e.g., phrases, sentences, or stories) related to the participants' pain and pain management experiences. These text units were each given a code, which is a word or short phrase that captured the essence of the data. The other team members verified the codes. Third, the primary investigator created a case-by-topic table.[49–50] The cases were presented on the vertical axis and topics of interest related to pain management (e.g., descriptions of pain, actions taking by clinicians, self-management of pain) were placed on the horizontal axis. Each code was placed in the appropriate cell. The codes in each column were summarized, and through team discussion and consensus, categories were developed. Emerging categories were discussed with participants during subsequent interviews to determine resonance with their experiences. Fourth, a narrative description of the categories in each column was written by the principal investigator and confirmed by the other team members.

Findings

Demographic and Medical Data

Twenty-eight patients met criteria and agreed to participate in the study. Because one patient appeared confused after she provided consent, she was not interviewed and her demographic/medical data were not used. The medical record of another patient who was interviewed could not be located. The findings reported here therefore are based on demographic/medical data from 26 patients (Table 1) but narrative interview data from 27 patients.

The median age of the participants was 58.5 years (IQR 26–41), range of 21 to 83 years. As seen in Table 1, more women than men participated. All the participants were Caucasian but one who was African-American. The participants' lengths of hospital stay were between 3 and 13 days. The majority of participants had no prior pain history or history of opioid use.

The most common tumor types were glioma/ glioblastoma/ oligodendroglioma/ oligodendroma and meningioma. Participants were diagnosed with all grades of tumors, with grade 1 being the most common. The tumor grade of 8 participants was not listed in the medical record. The most common tumor sites were frontal, frontotemporal, temporal, and posterior fossa. The tumors were located equally in the left and right hemispheres. The surgeries lasted between 150 and 984 minutes, and the majority of surgeries used an anterior approach. Most participants were sedated during surgery. The most frequently prescribed analgesics were fentanyl, hydrocodone-acetaminophen, acetaminophen, oxycodone-acetaminophen, and hydromorphone. Most participants were also prescribed dexamethasone.

Interviews

The median length of the interviews was 21 minutes (IQR 13–29) with a range of 7 to 50 minutes. Most of the participants were oriented and alert. A few were lethargic but still able to participate in the interview. Some participants provided many details and gave elaborate descriptions of their post-operative pain, whereas others were less verbose. The participants' demeanor during the interview varied; some were tearful, some appeared irritable, and some were in good spirits. This variation may well have been related to their level of pain. While the majority of the participants reported their pain had mostly subsided at the time of the interview, a few were in some pain. For a few of these participants, the primary investigator, in consultation with the participants, abbreviated the interview to reduce participant burden.

Pain Management Experiences

The analysis revealed that the participants' pain descriptions varied on two major dimensions: the degree to which pain was a salient concern in the context of their overall recovery while hospitalized and the complexity of their pain management experiences.

***Salience of pain*.—**The role of pain in the context of the participants' overall recovery experience varied considerably among the participants. For some, pain was not a salient concern and, despite the fact that the interviews were focused on pain experiences, these participants did not dwell on discussing their pain and often diverted the interviews to topics that were of more concern to them, such as the overall course of their treatment for their brain tumor or their plans for returning home. Often, these participants described their pain as "no big deal," and indicated it was expected, tolerable, or manageable. For other participants, however, pain was an important concern in their recovery experience and remained the focus of much of their interviews. In some cases, this was because the participants experienced pain that was particularly intense. These participants described their pain, at least at one time point, as excruciating, debilitating, or unbearable. In other cases, pain was a salient concern because it lasted a long period of time, was not well controlled, or interfered with recovery activities, such as physical therapy or diagnostic testing.

***Complexity of pain management experiences*.—**The complexity of participants' pain management experiences also varied considerably. Some participants described their pain management experiences as routine, simple, straightforward, and generally effective. These patients typically indicated that their level of pain was assessed, they received pain medication, and experienced relief. Other participants, however, described their pain management experiences as complicated, difficult, or trying. Complex pain management experiences could be related to side effects or complications of pain medications, pain that could not be well managed, conflictual interactions with clinicians, or other recovery complications that interfered with pain management.

To describe the participants' pain management experiences, therefore, we determined that participants might be placed in one of four potential groups (Table 2): 1) pain-as-non-salient, routine pain management; 2) pain-as-non-salient, complex pain management; 3) pain-as-salient, routine pain management; and 4) pain-as-salient, complex pain management. Based on information extracted from their narratives and the descriptions of the two dimensions described above, each participant could readily be placed in a group. As would be expected, no participants were placed in the pain-as-non-salient, complex pain management. Within each of the other three groups, common patterns of pain management experiences were identified, and each pattern was given a label that best captured how the participants described that pattern. Table 2 presents the patterns that comprised the groups. The groups and the patterns are described below with verbatim quotations from the participants that reflect each pattern.

Group 1: Pain-As-Non-Salient, Routine Pain Management

Twelve participants were placed in Group 1. For participants in this group, pain was not a salient concern in the overall context of their recovery and their pain management experiences were described as routine. Within this group, four patterns of pain management were described. These patterns are labeled as follows: 1) *Simply getting pain pills*, 2) *Conferring with staff*, 3) *Waiting the pain out,* and (4) *Having no pain at all*.

Simply getting pain pills.—Four participants described a pain management pattern that is best described as *simply getting pain pills*. These participants had minimal pain and described it as discomfort or tenderness. One participant stated that her pain "…wasn't a piercing pain. It was more like a discomfort" (ID 010, female, 76, grade III astrocytoma). Several were surprised at how little pain they had following surgery. This group described their pain management experience as simple and straightforward. Either the staff assessed the participants' pain or the participants asked for pain medication, the staff gave them pain medication, and the participants experienced relief. The same participant stated, "Well, basically,… they [the staff] would ask me, how do you feel? What's your pain level? And I would tell them….And um, they would address that with medication" (ID 010, female, 76, grade III astrocytoma).

The participants in this group also used various self-management strategies to deal with their pain. These strategies included sleeping, remaining still, placing wet washcloths on their foreheads, holding their incisions or surgical sites, and distracting themselves with other activities or thoughts.

Conferring with staff.—Five participants described a pain management pattern that is best described as *conferring with staff*. These participants also indicated that their pain was minimal and manageable. One participant said, "The pain hasn't been real terrible, not excruciating, so tolerable…I guess" (ID 028, male, 54, hemangioblastoma; grade not available). The participants in this group did not just receive pain medication routinely, but rather discussed plans for pain management with the staff. In some cases, this involved deciding how much medication to take (e.g. "one pill or two") or deciding when the best time to take the medication would be. For example, some participants discussed with staff when to take their pain medication so they could participate in therapy or go to sleep. As a result, the participants felt like they had some input into how their pain was managed. One participant stated,

> I like the fact that they would let me talk and know if indeed I felt I needed something [for pain] or if I thought I could get through, they treated me as if I was intelligent. [I would say], 'Let—let's wait another hour until the meds kick in and then I can maybe sleep through the night.' Or whatever like that. So when they walked you through like that, I appreciated that. (ID 025, female, 66, grade I subependyoma).

Some of the participants in this group also listed some self-management strategies that they used to deal with their pain. The strategies included dimming the lights and drawing the curtains, decreasing stimulation, and limiting visits from family and friends.

Waiting the pain out.—Two participants described a pain management pattern that is best described as *waiting the pain out*. These participants also had minimal pain. One described it as a "brain freeze" (ID 013, female, 64, schwannoma; grade not available) and the other as "very minor" (ID 022, male, 83, grade IV glioblastoma). Both of these participants thus just waited for their pain to go away by itself without taking any pain medication to manage the discomfort. One participant stated, "You just wait till it goes away. [You] just go over the hump and that's it" (ID 013, female, 64, schwannoma; grade not available).

These two participants mentioned some self-management strategies as well. One mentioned attempting to "leave the surgical site alone," (ID 022, male, 83, grade IV glioblastoma) and the other mentioned "working hard" to focus on her breathing (ID 013, female, 64, schwannoma; grade not available).

Not having pain at all.—One participant had no pain at all after surgery. He simply stated, "[My] head [doesn't] hurt" (ID 020, male, 67, grade I schwannoma). Pain management thus was not a concern, and accordingly, he did not need any self-management strategies.

Group 2: Pain-As-Salient, Routine Pain Management

Seven participants were placed in Group 2. For participants in this group, pain was a salient concern in the overall context of their recovery and their pain management experiences were described as routine. Within this group, two patterns of pain management were described. These patterns are labeled as follows: 1) *Definitely getting pain pills*, and 2) *Staying on top of the pain*.

Definitely getting pain pills.—Four participants described a pain management pattern that is best described as *definitely getting pain pills*. These participants had pain that was a concern for them because it was severe or enduring, especially soon after surgery. They described it as bad or severe. One participant said, "The pain [the first day] was extremely excruciating – I can't say the word. It was horrible" (ID 014, female, 48, grade I meningioma). Their pain management pattern was similar to that of *simply getting pain pills*, but because their pain was more problematic, getting medication was a more pressing concern. Another participant said, "I definitely took the pain medication" (ID 008, male, 65, grade IV oligodendroma). These participants' pain management, while more urgent, was nonetheless routine. They reported their pain to the staff, the staff gave them pain medications, and typically the pain subsided. If it did not, more pain medication was given that then did relieve the pain. One participant stated,

> As soon as I woke up, it was like, 'Oh, my, God, I'm in so much pain.' And they told me how much to rate it. And I said, 'A 20.' And she said, 'Okay.' She said, 'We're gonna give you something for it.' They didn't let me sit there long before they took care of the situation and gave me something to take care of it. But yeah, when I first came out of it, it hurt like a mother. (ID 014, female, 48, grade I meningioma)

Some of these participants also used self-management strategies to manage the pain. The strategies included using ice packs, practicing yoga and relaxation, meditating, and praying.

Staying on top of the pain.—Three participants described a pain management pattern that is best described as *staying on top of the pain*. These participants experienced severe pain, particularly in the first several days after surgery, and felt the pain was an obstacle to their recovery. Their pain management experience was marked by preemptive efforts not to let the pain take hold. They were vigilant about keeping the pain at bay because they recognized that it was harder to manage it once it occurred. In some instances, the staff stayed on top of the participants' pain by assessing it regularly. One participant stated, "They'd come in three of four times a day [and] would give me Norco or Valium or both depending on what I needed…They were pretty on top of keeping my pain in check, which was nice" (ID 004, male, 22, astrocytoma; grade not available). In other instances, the participants themselves planned ahead so the pain would not take hold. One participant described severe pain that recurred as soon as his pain medication began to wear off. He stated,

> So knowing that [the medication] lasts for four hours, four hours and ten or fifteen minutes is important, that way I can let these guys know like I did…because I know she's gonna be busy and that way she can get the pills and so forth …because I'm one of four or five people that she's taking care of…so I definitely wanted to let her know that I was ready for it. (ID 012, male, 28, grade II glioma)

The participants in this group also used a number of self-management strategies to deal with their pain. The strategies included deep breathing, rubbing or squeezing their heads, positioning themselves for comfort, and using heat or ice packs to dull the pain. Some called upon their faith and attempted to find meaning in their pain. One participant said he dealt with his pain by "leaning on Jesus" (ID 012, male, 28, grade II glioma). Others held family members' hands or talked to them to help manage the pain.

Group 3: Pain-As-Salient, Complex Pain Management

Eight participants were placed in Group 3. For participants in this group, pain was a salient concern in the overall context of their recovery and their pain management experiences were described as complex. Within this group, two patterns of pain management were described. These patterns are labeled as follows: 1) *Not staying on top of the pain*, and 2) *Having everything done to help me*.

Not staying on top of the pain.—Five participants described a pain management pattern that is best described as *not staying on top of the pain*. Their pain was particularly intense. One participant had excruciating pain following surgery. She said, "Oh, yeah, I was crying, shaking, all the nine yards" (ID 026, female, data not available). In some cases, the pain lasted for most of the recovery period. These participants' experiences were marked by a sense that staff were not invested in or able to "stay on top of" their pain. Another participant stated, "They were trying to give me Percocet and that takes about an hour to kick in, and my pain, they had trouble staying on top of it for a while, so they gave me an IV that kicked in right away, and then some Percocet on top of that…" (ID 007, male, 77, grade I hemangioblastoma).

In several cases, these participants had difficult pain management experiences because a number of factors complicated their pain treatment. These complications included severe nausea and constipation due to the pain medication, coughing that intensified the pain, adverse reactions to a pain medication, and problems managing high blood pressure or blood glucose. One participant who felt that her pain was a major factor interfering with her recovery stated, “I even think the blood pressure and all that can be very related to the pain and my blood sugar has been up and down. I think a lot of it has to do with the pain” (ID 026, female, data not available).

As a result, these participants described a somewhat complicated pain management regimen that changed frequently. Some were given a combination of intravenous pain medications, a variety of oral pain medications, and steroids. The participant mentioned above stated, “After the morphine it [the pain] got so much better…. But they were able to absolutely get me back on the Fentanyl without it dropping my oxygen even more, and then they’ve been giving Percocet and Vicodin. So that was what kept me pretty much not in pain” (ID 026, female, data not available).

The pain management experiences of these participants were also marked with some unsatisfying or conflictual interactions with staff. Some participants indicated that the staff did not give them the amount of pain medication they desired. These participants felt they were given either too many or too few pills. Others felt the staff did not give them the pain medication in a timely enough manner to keep the pain at bay. The participants’ pain management experiences were in some instances made worse because they felt the staff was not listening to them or understanding their experiences. One participant, for example, said she would have to repeatedly ask staff for pain medication but was told she was getting the strongest medication possible and she would “just have to wait” to get more (ID 018, female, 34, glioblastoma; grade not available). In some cases, the participants were able to negotiate a pain management regimen with staff that they felt was adequate, whereas others had more contentious interactions. Another participant said she was “hardheaded” but did not want to get into “a big argument” with the staff. She explained,

> They [staff] just asked me how much pain I was in. I gave them a number and they said, ‘What’s a tolerable – manageable pain for you?’ I said, ‘If it’s about a five. I’m good. If it starts to get up to a six, we need to start the fentanyl because after six, it starts to go up really quickly from there, so if I say it’s six, fentanyl time…’ But at one point, it wasn’t. Because I wasn’t getting the fentanyl every hour like I’m supposed to so, it would go back to, ‘Okay. We’ve got to get this every hour on the hour again.’ And so it got to the point where I’d be like, ‘Give me the fentanyl before you start doing your charting because then it will be an hour before you can get back in here because I can’t deal with going through this again.’ (ID 009, female, 36, pseudomeningocele; grade not available)

Like the other groups, some of these participants attempted to deal with their pain through using various self-management strategies. They used heat and ice packs, positioned themselves for comfort, and attempted to distract themselves from the pain by talking to others or watching television.

Having everything done to help me.—Three participants described a pain management pattern that is best described as *having everything done to help me*. These participants also experienced intense pain and had other experiences, such as severe nausea or a low pulse rate, which complicated their pain management regimen. One participant described how her pain management was complicated because her pulse went very low and staff had to initially withhold her pain medication, resulting in intense pain (ID 001, female, 59, grade I acoustic neuroma and schwannoma). The pain management regimens of these participants also included a variety of types of pain medication that were changed throughout the recovery period due to complications.

Unlike the other participants with complex pain management patterns, however, the participants in this group felt the staff were highly invested in managing the their pain, frequently checked on them, and were attentive and understanding. The participants had a sense that the staff did “everything in their power” to help manage the participants’ pain. One participant stated,

> The nurse was very nice to come in and she said, ‘Well, what can I do for you? Just tell me, what do you want me to do because I’ll do anything I can.’ And that in itself was nice to hear, and she was able to get me a medication to calm me down a little bit. (ID 016, female, 61, grade I schwannoma)

Another participant said, “They [the staff] did everything they can to possibly help me…. They have been there for me, ‘What can I do to help you?’” (ID 015, female, 54, grade III oligodendroma).

This group used many self-management strategies to address their pain and discomfort. These strategies included sleeping, relaxing, lying still, and trying to rest. They also relied on the support of family members coming in to visit to take their mind off of the pain. One said that crying helped manage the pain and another found eating to be helpful.

Discussion

All the participants but one had some pain following their craniotomies. Their descriptions of their pain experiences varied on two dimensions: the salience of pain in the context of recovery and the complexity of their pain management experiences. Based on these two dimensions, we divided the participants into three groups: (1) pain-as-non-salient, routine pain management, (2) pain-as-salient, routine pain management, and (3) pain-as-salient, complex pain management. Many participants, regardless of how salient their pain was, described a pain management experience that they considered as uneventful or routine. Their pain was managed to their satisfaction and involved primarily being given pain medication in a timely manner and experiencing the pain medication as effective. Other participants described pain management experiences that were more problematic. In some cases, this was because of the severity and nature of their pain, complications from surgery, or side effects of the medication. In a few cases, this was because of problematic interactions with clinicians who did not administer medications in a timely manner, listen to the participants’ pain-related concerns, or understand their pain experiences.

Our findings were consistent with those of several other studies that examined patients’ experiences with pain management while in the hospital. For example, a study by Farooq et al. examined hospitalized patients’ satisfaction with acute pain management after surgery.[50]

Just as the participants in our study were generally satisfied with their interactions with staff regarding pain management, these researchers reported that most patients in their study felt their pain was well managed and they were satisfied with their experiences with the hospital staff.[50] However, consistent with our findings, a few of the participants in the Farooq et al. study felt that their pain was not well controlled and that their pain medications were administered too late.[50] Our major finding – that the majority of patients had an uneventful course of pain management because they were given analgesics that managed their pain well – was similar to the finding of a study that revealed that head and neck cancer patients undergoing radiotherapy felt their pain was managed in a timely way.[51]

The experiences of the few of our participants who had problematic interactions with staff related to pain management was echoed in several other studies of hospitalized patients who experienced pain. For example, a study by El-Haddad et al. revealed that patients hospitalized with acute low back pain were unable to communicate the severity of their pain to staff and felt the staff minimized their pain,[52] a study Bernhofer et al. revealed that patients hospitalized with irritable bowel disease reported that they were judged or discredited by staff for experiencing pain,[53] and a study by Coleman et al. revealed that patients with sickle cell anemia reported they felt misunderstood or not believed when reporting their pain levels.[54] While problematic interactions with staff were reported in our sample, none of our participants discussed feeling stigmatized or doubted about their level of pain. This may suggest that the pain management experiences of hospitalized patients differ from those with acute pain being treated in the context of chronic pain conditions.

Finally, just as some of participants employed other “self-help” non-pharmaceutical strategies to manage their pain, women in a study by Hovind et al. who had undergone surgery for breast cancer employed their own pain management strategies including physical exercise, relaxation, and distraction.[55]

Our findings resonated with several constructs drawn from the theory of unpleasant symptoms (TOUS).[56–57] The TOUS has three major components: (1) measurable *symptoms*, (2) influencing *factors* that alter the patient’s experience of the symptom, and (3) the impact of the symptoms on functional and cognitive *performance*.[56–57] The theory indicates that symptoms have four measurable dimensions: intensity, timing, distress, and quality.[56–57] The components of the theory are evident in our study findings. For example, the theory indicates that situational factors, such as persons’ treatments, can affect how they experience symptoms. This proposition is consistent with our finding that whether participants considered their pain to be salient or non-salient was closely intertwined with whether they considered their pain management experiences to be routine or complex. Moreover, the component of the theory that stresses the role of symptoms on functional performance was also evident in our findings as whether pain interfered with recovery from surgery and ability “to start rehab” influenced whether the participants’ pain was salient or non-salient. Finally, all the symptom dimensions outlined in the theory appeared in our findings. These symptom dimensions were evident in the narratives of participants whose pain was non-salient as they discussed pain intensity (“not too bad”), timing (“pain would just go away”), quality (“more like tenderness’), and distress (“nothing that couldn’t be managed”). Similarly, the dimensions were also evident in the narratives of participants whose pain was salient as they also described intensity (“excruciating”), time (“long-lasting”), and distress (“crying, shaking”).

Limitations

There are several limitations to this study. First, because our participants were hospitalized patients who had undergone anesthesia, and most were taking pain medications, it is possible that their memories of their experiences with their pain and/or how it was managed might have been impaired. Some may have had some pain experiences, especially right after surgery, that they could not fully describe, and this might account, in part, for why some described their overall pain experiences as non-salient. In addition, the use of a single study site and unit may impact our participants’ overall level of satisfaction in part due to that unit’s pain management practices. Moreover, minorities were underrepresented in our sample. While non-Hispanic whites are diagnosed with brain tumors more frequently than other minorities,[2] the experiences of minority patients were not well represented in our study, and we cannot ascertain if they have different pain management experiences. Another limitation was that while we obtained robust data on how the participants viewed their pain and how it was managed pharmaceutically, data regarding self-management strategies was mentioned in passing and we did not probe for additional information regarding these strategies. Therefore, we can make few claims about how self-management strategies figured in the participants’ overall pain management experiences.

Future Research

In order to further advance our understanding of the pain management experiences of patients who have undergone a craniotomy, we suggest conducting studies at multiple sites to ascertain which pain management experiences might be related to the practices of specific units or institutions. Moreover, obtaining a larger and more diverse sample would allow for exploration of differences in pain management experiences due to demographic factors, such as age or race/ethnicity, and factors related to the type of surgery and the type tumor. To understand how pain management experiences unfold over time, a mixed-method study that combines clinician observations, quantitative clinical data such as pain ratings and medication dose, and narratives of patients’ subjective experiences throughout the recovery period would be optimal. Such studies would shed more light on the phenomenon of uncontrolled surgical pain in this population.

Clinical Implications

In 2016, clinical practice guidelines for the management of postoperative pain were presented by the American Pain Society, the American Society of Regional Anesthesia and Pain Medicine, and the American Society of Anesthesiologists’ Committee on Regional Anesthesia, Executive Committee, and Administrative Council.[58] These guidelines provided recommendations for a number of aspects of pain management for postoperative patients, including preoperative education, perioperative pain management planning, and use of a variety of pharmacological and nonpharmacological modalities. However, few of the recommendations were supported by high-quality evidence, pointing on the need for more research to guide pain management in this population.

The findings of our study suggest some clinical implications, especially in regards to staff interactions that provide the context for pain management. While many of the participants were satisfied with their pain management experiences, others felt their pain management was problematic as they perceived it to be ineffective and staff as nonattentive. These patients would benefit from indications that staff are attuned to “staying on top” of their pain and receiving information regarding how their pain will be managed. Pain management best practices, such as regular identification and timely treatment of the side effects and comorbidities that complicate pain management, administration of pain medications in a timely fashion before the pain “gets out of control,” continual assessment of the effectiveness of the medication regime, and consideration of alternative analgesics when needed, are especially important for these patients. Good patient/clinician communication, in which patients feel heard and understood and have input into decisions made regarding their pain management, is foundational to a good pain management experience. Clinicians should also explore with patients what self-management strategies would be acceptable to them and which might enhance their pain management experiences.

Conclusion

The experiences of patients who have undergone a craniotomy vary according to the nature of the pain they experience and their unique experiences of how it is managed. Despite some clinician beliefs that post-craniotomy pain is minimal, our findings confirm that for some patients it is a salient experience that causes distress and interferes with their recovery. Our typology of three distinct types of pain management experiences, if further developed and validated, could advance our understanding of the diversity of pain experiences following craniotomy and the identification of the unique clinical needs of distinct groups of post-craniotomy patients. The study confirms that the nature of patient interactions with clinicians clearly influence patients’ pain management experiences.

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Table 1.

Demographic and Medical Record Data (n=26)[a]

Age	**Median 58.5 years; IQR 26–67; range 21–83 years**	
		n (%)
Gender	Female	15 (57.7)
	Male	11 (42.3)
Race	Caucasian	25 (96.2)
	African American	1 (3.8)
Tumor type	Non-glial (meningioma, ependymoma, schwannoma)	12 (46.2)
	Glial (glioma, glioblastoma, oligodendroglioma, oligodendroma, astrocytoma)	9 (34.6)
	Other (hemangioblastoma, hamartoma, carcinoma)	5 (19.2)
Tumor grade	I	11 (42.3)
	II	2 (7.7)
	III	2 (7.7)
	IV	3 (11.5)
	Not stated	8 (30.8)
Tumor location	Supratentorial (frontal, frontotemporal, temporal/vestibular, parietal, parieto-occipital, suboccipital	16 (61.5)
	Infratentorial (cerebellar, skull base, posterior fossa)	7 (26.9)
	Not stated	3 (11.5)
Tumor Hemisphere	Right	15 (57.7)
	Left	11 (42.3)
Surgical Approach	Anterior	25 (96.2)
	Posterior	1 (3.8)
Type of craniotomy	Sedated	17 (65.4)
	Awake	9 (34.6)
Analgesics prescribed[b]	Fentanyl	23 (88.5)
	Hydrocodone-acetaminophen	15 (57.7)
	Acetaminophen	14 (53.8)
	Oxycodone-acetaminophen	9 (34.6)
	Hydromorphone	6 (23.1)
	Morphine	5 (19.2)
	Oxycodone	4 (15.4)
	Ibuprofen	2 (7.7)
	Lidoderm	1 (3.8)
	Acetaminophen-codeine	1 (3.8)
	None	1 (3.8)
Steroids prescribed	Dexamethasone	22 (84.6)
	Hydrocortisone	1 (3.8)
	None	3 (11.5)

Age	**Median 58.5 years; IQR 26–67; range 21–83 years**	
		n (%)
Prior pain history	No	24 (92.3)
	Yes	2 (7.7)
Prior opioid use	No	25 (96.2)
	Yes	1 (3.8)

[a] While 28 persons provided consent, one person was not interviewed due to confusion that became apparent after consent was obtained and the medical records of one participant could not be obtained from the institution. Thus we have demographic and clinical information for 26 participants.

[b] Some participants were given more than one type of analgesic.

Table 2.

The Four Potential Post-craniotomy Pain Management Groups

	Routine Pain Management	Complex Pain Management
Pain-as-non-salient	**Group 1** Simply getting pain pills Conferring with staff Waiting the pain out Having no pain at all	
Pain-as-salient	**Group 2** Definitely getting pain pills Staying on top of the pain	**Group 3** Not staying on top of the pain Having everything done to help me