

# Knowledge, and attitudes of patient's primary caregiver towards decompressive hemicraniectomy

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## Abstract

**Background:** Decompressive hemicraniectomy (DHC) is a surgical procedure in which a substantial piece of the cranium is removed to reduce intracranial pressure. DHC improves mortality. Although the surgical procedure may be lifesaving, many survivors suffer from a severe neurological impairment, which the patients and primary caregivers have to deal with afterward. This study's purpose is to understand better the primary caregiver's perception regarding the burden of the outcome of DHC. **Methods:** This was a descriptive, prospective study that included all primary caregivers of patients who had previously undergone DHC between the years 2019 to 2022 at Jose R. Reyes Memorial Medical Center. A total of 48 primary caregivers were included in the study. **Results:** Most primary caregivers have adequate knowledge of the pros and cons of the surgery, but few individuals demonstrated insufficient knowledge. Moreover, the primary caregivers also acknowledged the reality of the patient's surgery, including the demand for the caregiver's time and other negative effects.

**Conclusion:** There is still a need to comprehensively orient the patient's primary caregivers on the benefits and risks of DHC to ensure they know what to expect prior to the surgery. Also, fear of the negative outcomes of the surgery, family concerns, and finances were the main hindrances why other primary caregivers may opt out of the surgery.

**Keywords:** Knowledge, attitude, primary caregiver, decompressive hemicraniectomy

## INTRODUCTION

Decompressive hemicraniectomy (DHC) is a surgical procedure in which a substantial piece of the cranium is removed to reduce intracranial pressure.<sup>1</sup> It is a surgical therapy option for malignant middle cerebral artery infarction, lobar intracerebral hemorrhage, large-volume intracranial tumors with edema, and severe aneurysmal subarachnoid hemorrhage.<sup>2</sup> In these life-threatening disorders, DHC has been demonstrated to lower mortality.<sup>3</sup> Decompressive surgery aims to relieve pressure on the brain, allow edema to expand, restore cerebral perfusion, and improve retrograde perfusion via collateral arteries of the leptomeninges.<sup>3</sup>

DHC reduces mortality. However, the issue amongst physicians has been that many survivors will suffer from a severe neurological impairment, which the patients, relatives, and primary caregivers will have to deal with. Therefore,

several questions remain: What is the primary caregiver's perception regarding the outcome's burden after hemicraniectomy? Does the primary caregiver accept the challenge of long nursing care and the patient's financial needs? Can the primary caregiver accept the sacrifices and additional responsibility; are they willing to give up their time to care for the patient? And are they still willing to consent to do the same procedure after experiencing these responsibilities?

Because the relatives or the primary caregiver should most likely answer these questions, the purpose of this study is to gain a better understanding of the perception of the primary caregiver regarding the burden of the outcome of DHC. This may help clinicians guide discussions on consent and assist family members in making tough judgments regarding such surgical procedures. Likewise, to our knowledge, no similar studies locally have been published to answer these questions.

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Date of Submission: 25 April 2023; Date of Acceptance: 9 May 2023

<https://doi.org/10.54029/2023mii>

Furthermore, this is of interest as many factors, such as financial status, culture, and beliefs, may be different and significantly influence the future decision of the patient's relative in giving consent for the procedure.

This study investigates the knowledge and attitudes of primary caregivers of patients who underwent DHC towards this surgical procedure.

#### *Review of related literature*

DHC is commonly used in patients with malignant infarction, and several studies have been conducted. Three European randomized controlled trials looked at the effect of decompressive surgery on the functional outcome of patients with malignant MCA infarction. These studies are the French DECIMAL (decompressive craniectomy in malignant middle cerebral artery infarcts) trial, the German DESTINY (decompressive surgery for the treatment of malignant infarction of the middle cerebral artery) trial, and the Dutch trial HAMLET (hemicraniectomy after middle cerebral artery infarction with life-threatening edema trial). These trials have a similar design and randomized patients into decompressive surgery or medical treatment.

All of the trials share the same primary outcome. A meta-analysis was conducted with pooled data from these studies, which showed that out of 42 patients that were treated conservatively, 33 (78%) patients scored mRS  $\geq 4$  after 12 months of treatment, while patients in the surgery group showed 29 (57%) out of 51 patients scored mRS  $\geq 4$  after 12 months of treatment. The remaining 7 (22%) of patients treated conservatively scored mRS  $\leq 3$  after 12 months of treatment, while 22 (43%) patients treated surgically scored mRS  $\leq 3$  after 12 months of treatment.<sup>4</sup>

In addition, one study conducted by Chua *et al.* in the Philippines last 2015 with almost the same research design and primary outcome as the 3 European randomized controlled trials regarding hemicraniectomy for malignant middle cerebral infarction showed that 4 out of 11 patients (38.4%) treated medically and 3 out of 13 patients (23.1%) treated surgically had a good functional outcome (mRS  $\leq 3$ ) at 6 months, while 6 out of 11 patients (54.5%) that were treated medically died compared to 5 out of 13 patients (38.5%) that were treated surgically.<sup>5</sup>

A study conducted by Green *et al.* in Canada last 2015 regarding the impact of life, family outcomes, and caregiver burden after DHC. Based on the findings, it showed that one family stated

that the stress and financial load of dealing with the consequences of long-term stroke survival shattered their family system. Also, some caregivers reported a reduction in formal support service after discharge, and several caregivers disclosed that they have financial burdens due to reduced work or resignation just to be at home caring for the patient. This study also asked the subjects regarding their decision-making at the time of the stroke; 26 patients and 12 caregivers agreed with the decision made at the time and would do it again. Only one patient and one caregiver (spousal partners) disagreed with the choice to have life-saving surgery to treat the stroke.<sup>6</sup>

Additionally, one study conducted by Kwan *et al.* in the United States last 2018 concerning long-term outcomes and ethical considerations of DHC showed that four out of five patients who have experienced DHC will still give retrospective consent to the same procedure. Most of the patients who provided retrospective consent are the ones who achieved modified Rankin scores of four or better.<sup>7</sup> Moreover, a study conducted by Ragoschke-Schumm *et al.* in Germany last 2015 regarding retrospective consent to hemicraniectomy after malignant stroke among older people showed that 80% of most participants will still agree and consent retrospectively for hemicraniectomy, despite the impaired functional outcome they experienced.<sup>8</sup>

Furthermore, another study conducted by Neugebauer *et al.* in Germany last 2016 regarding attitudes of patients and relatives toward disability and treatment in malignant MCA infarction showed that most of the participants still preferred doing DHC over intensive care treatment and palliative treatment, regardless of the hemisphere affected.<sup>9</sup> There are currently no studies looking into the knowledge and attitudes of Filipinos regarding DHC. This is of interest as many cultural and social factors may be different compared to the Western countries and may significantly influence the decision to consent to the procedure.

## **METHODS**

### *Study design*

This was a descriptive, prospective study of the knowledge and attitudes of the patient's primary caregiver toward DHC.

A primary caregiver is defined as a person who is a first-degree relative of a patient and indicates a close relationship with the patient. They are also

the one who has the sole decision maker and the one who tends to the patient for a minimum of 8 hours per day. We excluded those being paid to care for the patient (i.e., personal nurses, maids, etc.). The patient's primary caregiver was asked to answer questions based on what they knew and considered acceptable and necessary concerning DHC as a treatment modality in the hypothetical case of a future neurological emergency.

### *Subject selection*

This study included all primary caregivers of patients who had previously undergone DHC between the years 2019 to 2022 at Jose R. Reyes Memorial Medical Center. This study included the patient's primary caregiver, age 18 years old and above, a primary caregiver of a patient who underwent DHC, survived six months after the procedure, and was willing to participate in the study.

The exclusion criteria were that primary caregivers of patients who underwent DHC but died six months after the procedure and those who did not consent to the study were excluded from this study.

### *Data collection, methods, and tool*

This study utilized a questionnaire created by the researchers. The items included in this questionnaire were based on the summary of the published literature reviewed, following the study's objectives. The primary investigator and its advisers evaluated the questionnaire's content, and was pilot tested to a group of primary caregivers of patients who underwent DHC. The data analyst statistically reviewed and validated this using Cronbach's alpha, which scored 0.702, greater than the acceptable value of 0.70.

All primary caregivers of patients who underwent DHC and were discharged from Jose R Reyes Memorial Medical Center from the year 2019 to 2022 were followed up at or after six months after the procedure, were contacted via phone call, and scheduled for an interview. A face-to-face interview with the patient's primary caregiver was carried out. Informed consent was conducted before data collection.

The questionnaire was written in English and Filipino separately. It was a 15-item questionnaire consisting of two pages with one topic section for each field: knowledge and attitude. The table on the right shows the distribution of items in each subpart. Types of responses include a Likert scale, yes/no answer, and selection among enumerated

choices. The Likert scale for the knowledge part has the following responses: 4 (strongly agree), 3 (agree), 2 (disagree), and 1 (strongly disagree). The attitude part has both yes/no questions, but some part has a selection among enumerated choices for each response.

Data were presented as percentages to show distribution. Every response in the questionnaire was rated, and a total score was given based on the patient's primary caregiver's knowledge and attitude. For the knowledge part, those who answered "agree" and "strongly agree" were considered adequate knowledge per item. The mean score was computed to get the interpretation for knowledge, and if it is above the assigned value, it is considered "adequate knowledge." For the attitude subpart, the yes response was considered "positive," and the no response was "negative."

## **RESULTS**

Ninety-two patients underwent DHC at Jose R. Reyes Memorial Medical Center from 2019 to 2021. Out of 92 patients, only 59 patients were discharged. Eight of 59 patients died six months after discharge, and four were lost to follow-up. A total of 48 primary caregivers were included in the study. (Figure 1)

This analysis shows that out of the 48 patients' caregivers, 41.70% strongly agreed, and 45.80% agreed that the patient would become dependent and experience moderate to severe disability after the surgery. On item 2, 52.10% strongly agreed, and 45.80% agreed that people who underwent head surgery need intensive attention. In comparison, 43.80% strongly agreed, and 47.90% agreed on item 3, which states the necessity of long-term pharmacological treatments for patients who have had head surgery. Furthermore, 58.30% strongly agreed, and 33.30% agreed they needed long-term care. For item 5, 62.50% strongly agreed, and 29.20% agreed that caring for people who had head surgery takes a lot of financial money. For item 6, 70.80% strongly agreed, and 25% agreed that there is a need for follow-up check-ups after surgery.

As shown in this table, the percentage of the responses "strongly agree" and "agree" is higher than those who disagree, implying that most of the participants understand the procedure and are aware of it.

Table 2 shows that most participants strongly agree with all the statements. The majority of the patients' caregivers strongly agree that the patient

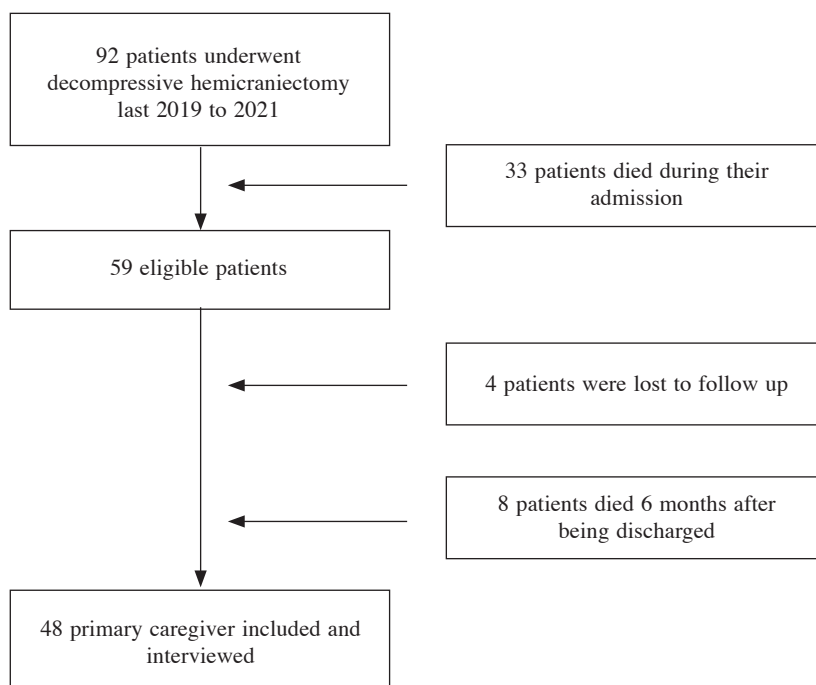


Figure 1. Flow chart of the study

will become dependent and will have moderate to severe disability ( $x=3.29$ ), that people who have had head surgery need intensive attention ( $x=3.50$ ), need long-term pharmacological treatment ( $x=3.35$ ) and long term care ( $x=3.50$ ), that it takes lot of financial money to care for them( $x=3.54$ ) and, that there is a need for follow-

up check-ups after surgery. In all the items, the participants demonstrated an adequate knowledge of DHC. In general, the caregivers have enough knowledge of the procedure.

Table 3 presents that 97.90% of the 48 patients' primary caregivers believed caring for a head surgery patient adds to their responsibilities as

**Table 1: Percentage distribution of the knowledge of patient’s primary caregiver towards decompressive hemicraniectomy**

Statements	SA (4)	A (3)	D (2)	SD
1. There is a high chance that after surgery the patient will become dependent and will have moderate to severe disability.	41.70%	45.80%	12.50%	0%
2. Do people who have had head surgery need intensive attention.	52.10%	45.80%	2.10%	0%
3. Do people who have had head surgery need long term pharmacological treatment.	43.80%	47.90%	8.30%	0%
4. Do people who have had head surgery need long-term care.	58.30%	33.30%	8.30%	0%
5. It takes a lot of financial money to care for people who have had head surgery.	62.50%	29.20%	8.30%	0%
6. there is a need for follow-up check-ups after surgery.	70.80%	25%	4.20%	0%

SA: Strongly agree, A: Agree, D: Disagree, SD: Strongly disagree

**Table 2: The overall knowledge of the patient's primary caregiver towards decompressive hemicraniectomy**

Statements	M	Value	Interpretation
1. There is a high chance that after surgery the patient will become dependent and will have moderate to severe disability.	3.29	SA	Adequate
2. Do people who have had head surgery Need intensive attention.	3.50	SA	Adequate
3. Do people who have had head surgery need long term medication and treatment.	3.35	SA	Adequate
4. Do people who have had head surgery need long- term care.	3.50	SA	Adequate
5. It takes a lot of financial money to care for people who have had head surgery.	3.54	SA	Adequate
6. There is a need for follow-up check-ups after surgery.	3.67	SA	Adequate

SA: Strongly agree

family members. Around 68.80% believed that their health had been affected since they began caring for the patient and 72.90% believed that it consumes their personal time, and 62.50% said that their life plans changed since they started caring for the patient. A total of 91.70% agreed that it is more acceptable for a patient to have undergone surgery, regardless of the outcome, than to see them die without trying possible ways to save them. For long-term care for patients who

underwent head surgery, 97.90% of their primary caregivers agreed to provide it, while 93.80% agreed to fund the patient's long-term needs. Furthermore, 83.30% of participants said yes when they were asked If they would undergo surgery if in case what happens to the patient happens to them, and 93.80% of them said that they would allow their relatives too when necessary.

The table shows that most patients' primary

**Table 3: Attitude of the patient's primary caregiver towards decompressive hemicraniectomy**

Statements	Yes	No
1. I believed that caring for a head surgery patient adds to my responsibilities as a family member.	97.90%	2.10%
2. I believed that my own health has been affected since I began caring for a head surgery patient.	68.80%	31.30%
3. I believed that caring for a head surgery patient is consuming more of my personal time.	72.90%	27.10%
4. I believed that my life plans have changed since I took care of the patient who underwent head surgery.	62.50%	37.50%
5. It would be more acceptable for me to see a patient who had surgery alive, regardless of the outcome than to die.	91.70%	8.30%
6. I agree to provide long-term care for patient who underwent head surgery.	97.90%	2.10%
7. I agree to fund for the long-term needs of patient who underwent head surgery.	93.80%	6.30%
8. If what happened to the patient happened to you and you also needed head surgery, would you have surgery.	83.30%	16.70%
9. The next time you have a relative who needs head surgery, you will you have it operated on	93.80%	6.30%

caregivers have positive attitudes toward DHC. Most acknowledge that caring for a head surgery patient greatly affects their life and health. Regardless of the difficulties associated with caring for the patients, most primary caregivers agree that they are willing to provide the care and funds they need as long as they are capable.

It is also revealed that caregivers still demonstrate negative attitudes, particularly towards the surgery, wherein 23% say they would not consent to head surgery even if they and their family members need it. The researchers code the reasons behind their dissent as the 3F's.

#### *The 3Fs: Fear, family burden, financial*

It was discovered that 23% of the 48 caregivers responded "NO" to head surgery, and the reasons behind their dissent are summed into 3 Fs. The last two items of the attitude survey, presented in Table 3, show why they will not undergo head surgery when necessary. The first common reason is fear. Most participants responded that they were afraid of the harmful outcomes of the surgery, such as complications during and after the procedure. The second underlying reason is the Family burden. The participants said no to head surgery because they didn't want to burden their families. This result can be understood in light of the participants' difficult experiences caring for their families undergoing surgery. It was discovered that their life and health changed when they began caring for the head surgery patient, which alone influenced their attitude towards DHC. Lastly, finances are one of the reasons some said no to head surgery. The participants claimed that when they started caring for the head surgery patient, money became an issue for purchasing medicines and medical equipment; some stated that borrowing money is required to purchase medicines and medical supplies.

## **DISCUSSION**

The main objective of this study is to investigate the knowledge and attitude of primary caregivers of patients who underwent DHC. The fact that some still disagree with the statements implies that few caregivers don't have enough knowledge of DHC. Results found that most primary caregivers have adequate knowledge of the benefits and risks of the surgery. However, there are still a few individuals who demonstrate insufficient knowledge. This result may be explained in light of participants' encounters with the patients they once cared for. For instance, they may have believed that the

patient would recover with a mild disability after the surgery, but this is not what happened. Their experiences have affected their overall judgment of the statements assessing their knowledge of head surgery. Moreover, the caregiver's attitude towards the surgery may be understood in the current situation of the participants. The fact that primary caregivers acknowledged the realities affiliated with the patient's surgery, such as personal time consumption, the change of plans, and other negative consequences, concludes that they are doing their best and are willing to care for their family members who need medical attention.

Likewise, regardless of the outcome after DHC, most participants would still prefer to undergo DHC, and most of them will also advise their relatives to undergo DHC. While 8 (16%) out of the 48 caregivers disagree with undergoing DHC due to three main reasons: fear of the complication and hesitation to pass on the burden and difficulty of taking care of an operated patient.

Finances are the most common barrier to medical treatment or surgery, which is not surprising since long-term care and medical treatment require a huge amount of money. Whether families like it or not, they must consider finances before letting a family member go through the surgery. While some organizations are willing to help, it is not sufficient to address all of the patient's needs. This scenario is especially true in the Philippines, as the medical system and reimbursement laws require most families to pay out of pocket for these procedures.

There are some limitations to this study. First, this study includes all patients who underwent DHC regardless of the cause. There may be a difference regarding the outcome and the nursing care needed if the study included specifically patients who underwent DHC due to malignant infarction only. Next, is that this study was done in a government hospital setting in the Philippines, where resources are limited. A comparative study with participants from a private hospital may help elucidate key socioeconomic, belief, and cultural factors affecting their decision and responses.

In conclusion, there is still a need to comprehensively orient the patient's primary caregivers on the procedure's benefits and risks to ensure they have enough knowledge of what will happen before the surgery. Furthermore, it can be concluded based on the findings that primary caregivers also need attention from medical practitioners since most of them reported that their health is affected once they start caring for patients who underwent surgery.

Fear of the negative outcomes of the surgery, family concerns, and finances are the main barriers to why other primary caregivers disagree with DHC.

The researchers recommend a brief orientation among the primary caregivers on the pros and cons of and after decompressive hemicraniectomy before the surgery to ensure that the primary caregivers are prepared to commit to the need to provide long-term care and medical treatment of the patient undergoing DHC. It is also recommended that concerned medical practitioners have a general health check-up especially designed for the primary caregivers to prevent serious health problems associated with their responsibility as caregivers of patients who had head surgery.

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