

ORIGINAL ARTICLE

Factors affecting surgery decision-making in patients with a chronic neurovascular condition

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Aims and objectives. To explore the factors that affect patient decision-making for an elective surgery.

Background. Cerebral cavernous malformations are lesions found in the brain and spinal cord comprised of abnormal blood vessels, which bleed sporadically causing serious neurological deficits. Course of treatment for cerebral cavernous malformation is often ultimately left up to the patient, and can include symptom management or surgery. Decision-making for surgery in life-threatening conditions has been well documented in the literature. Less extensive research has focused on elective surgeries, where patients have a choice. There has been no research on the factors that affect decision-making for cavernous malformation patients.

Design. Correlational self-report survey.

Methods. In part of a larger online study, participants were asked to rate the importance of six factors on their decision-making about surgery for cavernous malformation.

Results. Factors that were rated most important for individuals' decision-making included doctor's opinion regarding surgery, presence of disabling symptoms, fear of symptoms getting worse or developing new symptoms, and availability of an expert surgeon. Results indicated that these were rated as more important than having social support during recovery or having the means to pay for surgery. Additionally, having social support during recovery was rated as significantly more important than having the means to pay for surgery.

Conclusions. Factors that affect decision-making for patients diagnosed with cavernous malformation were similar to those found with other medical conditions requiring elective surgery. This study will assist healthcare workers in understanding the decision-making process of individuals who may choose an elective surgery for potentially disabling conditions with uncertain outcomes.

Relevance to clinical practice. Understanding the complex factors that affect decision-making in cavernous malformation will assist healthcare professionals to better communicate and support patients in their elective surgery decision-making.

Key words: Decision-making, elective surgery, neurovascular condition

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What does this paper contribute to the wider global clinical community?

- Provides information to clinicians about factors that impact patient decision-making with regard to elective surgery.
- Highlights the influence of clinician recommendations on patient choice about whether to have elective surgery.

Introduction

Cerebral cavernous malformations (CMs) are lesions found in the brain and spinal cord comprised of abnormal blood vessels, which bleed sporadically causing serious neurological deficits (Angioma Alliance, 2010). The diagnosis of CM, rare in the general population, can be associated with wide variation in type and degree of neurological symptoms, ranging from no symptoms to severe disability. There is a high degree of uncertainty associated with this diagnosis, as it is unknown what leads some patients to become symptomatic, and experience new neurological deficits at any time, while others remain healthy (Angioma Alliance, 2010).

Choices in treatment for CM include symptom management or surgery (Angioma Alliance, 2010). Doctors provide recommendations about the decision to have surgery, but the decision is often ultimately left up to the patient, weighing the estimated course of untreated CM against the risks and benefits of surgery (Hoch, 2010). While patients with CM have been studied with regard to aetiological factors, there have been no studies to date focused on patients' subjective experiences around treatment decision-making, especially given the often failed attempt of surgery to manage symptoms for individuals experiencing CM (Barrow 2012). Preservation of quality of life, degree of impairment in physical functioning, doctor's opinion, and improving survival rates have been shown in the literature to be important factors in patient decision-making on whether or not to have surgery for other various conditions (Murray *et al.* 2009, Fisher *et al.* 2012, Anderson *et al.* 2013, Jorgensen *et al.* 2013). Medical decision-making has been studied extensively in regard to medical conditions that require treatment, with the alternative to treatment being death (e.g. cancer; Jorgensen *et al.* 2013, Sidana *et al.* 2012, Stafford *et al.* 1998). There is less research available pertaining to patient perspectives on medical decision-making for elective surgery, with the alternative to surgery being symptom management.

Background

Cavernous malformation

CMs are well-defined lesions of potentially significant size that may be discovered as an incidental finding on an MRI or CAT scan, or may be present with disabling symptoms (Robinson *et al.* 1991). While the incidence of CM in the general population is 0.5%, about 12% of these individuals are not symptomatic (Porter *et al.* 1997). Haemorrhaging

(bleeding) is present in up to 25% of patients (Porter *et al.* 1997) and is considered one of the most serious complications for a patient experiencing CMs as it leads to a variety of debilitating symptoms. When accompanied by symptoms, some of which may be caused by haemorrhage, patients who have CM can experience seizures (about 36%), neurological deficits (either progressive or transient), or headaches (Porter *et al.* 1997). The most common patient complaints when they first see a physician are double vision, weakness, and sensory disturbances (Porter *et al.* 1997). The most disabling symptoms or complications of CM are seizures and haemorrhages. While haemorrhages have a low annual incidence rate (<1%), the risk of bleeding depends on the location of the CM, such that deep lesions in the brainstem have a higher tendency to bleed and cause serious problems to individuals (Porter *et al.* 1997).

The two main treatment options for patients with CM are surgery or symptom management (Porter *et al.* 1997). During decision-making as to which treatment option to pursue, various factors are considered: the patient's age (since surgery may be less successful for older people, and there is more time for disabling symptoms to develop in younger people), the location of the lesion, and the associated risk for neurological deficit with surgery, the patient's current symptom severity and discomfort, the frequency of haemorrhage, progressive neurological deterioration, and epilepsy (Robinson *et al.* 1991). The removal of lesions through surgery may help prevent subsequent bleeding, control epilepsy and prevent further neurological deterioration (Robinson *et al.* 1991).

Patient decision-making in life-threatening conditions

A variety of studies have investigated factors that affect decision-making for patients who have a choice to undergo surgery in many different medical conditions. A meta-analysis reviewed the factors affecting decisions of patients with chronic kidney disease to have renal replacement therapy, withholding or withdrawing dialysis or renal transplant (Murray *et al.* 2009). Individuals with chronic kidney disease often have a choice in their desired treatment. The most important factors in decision-making determined by the meta-analysis were: interpersonal relationships, such as the opinions of family and providers, provider-patient interactions and trust in providers; preservation of current quality of life, specifically concern about the impact that surgery would have on current daily functioning; need for control, or a desire to be in charge of their own future and manage the situation; personal feelings of the benefit or risk

of the procedure, specifically balancing willingness to take a chance with the fear of negative outcomes (Murray *et al.* 2009).

Research with patients living with colorectal cancer who have a choice regarding chemotherapy has found that reducing the risk of re-experiencing cancer is the most highly rated factor for choosing chemotherapy (Jorgensen *et al.* 2013). The same study found that having a doctor who the patient trusts and is comfortable with is also rated highly in contributing to the decision-making process. Similar to those living with chronic kidney disease, returning to previous quality of life was found to be an important factor in this sample. Factors of lowest importance for decision-making influencing chemotherapy treatment decisions included travelling for treatment, treatment cost, avoiding side effects, and the opinion of family (Jorgensen *et al.* 2013). A study by Sidana *et al.* (2012) asked men living with prostate cancer about the treatment method they chose and their rationale. The doctor's recommendation was found to be the most influential factor in decision-making regardless of the treatment chosen by the patient (Sidana *et al.* 2012). Reasons for choosing surgery over other treatment options included the assumption that surgery offered the best chance of a long-term cure and a high treatment success rate (Sidana *et al.* 2012). A study of women living with breast cancer also found that fear of cancer recurrence and belief in improved survival rates are the main reasons that women choose mastectomy in comparison to other treatment methods (Fisher *et al.* 2012). It appears that in cancer research, surgery is the preferred choice by patients even if they are given other treatment options. Factors that are most important for cancer patients appear to be reducing the risk of cancer returning, the doctor's opinion, and perceived improved survival rates. Preference for surgery in cancer patients is likely due to cancer being a life-threatening illness, where surgery is the best option for eliminating the disease.

Elective surgery decision-making

Various studies have looked at the factors that affect decision-making in nonlife-threatening conditions. Elective surgery, where the decision to have surgery is left up to the patient and abstaining from surgery will not result in death, is used as a treatment method in some gynaecological conditions (Uskul, Ahmad, Leyland, & Stewart, 2003). When given a choice, the most important factors for a sample of women with gynaecological symptoms in making a decision about undergoing hysterectomy were found to be the pres-

ence of disabling symptoms such as abnormal bleeding, and pain that decreased their quality of life (Uskul, *et al.*, 2008). Some women also stated that their doctor's and family's opinions were important in the decision-making process (Uskul *et al.*, 2008).

A study of adult deformity patients diagnosed with scoliosis found that the factor most important in decision-making to have surgery was functional limitations due to the disorder, which were found to be more important than pain caused by scoliosis (Pekmezci *et al.* 2009). In contrast to scoliosis patients, pain was found to be an important factor for patients choosing an elective amputation, in addition to functionality of the limb, and reduced quality of life due to physical limitations (Quon *et al.* 2011). Participants stated that they made their decision regardless of support from family and friends (Quon *et al.* 2011). A study of family involvement in elective surgery in Taiwan found that family well-being was the largest concern in making a treatment decision (Lin *et al.* 2013).

About 50–70% of individuals with symptomatic CM experience seizures (Angioma Alliance, 2010). Comparing individuals with CM to those who have been diagnosed with epilepsy may be of importance in understanding decision-making factors for surgery. Individuals with refractory epilepsy who opt to have surgery will be seizure-free approximately two-thirds of the time following the procedure (Anderson *et al.* 2013). Although the results are favourable, many patients do not consent to the procedure. The most important factors in the decision to have surgery were: frustration with epilepsy, the desire to be seizure-free, and the severity, frequency, and length of time with seizures (Anderson *et al.* 2013). Patients also stated that their epilepsy doctor was the most influential person in their decision-making (Anderson *et al.* 2013). Decision-making in patients living with epilepsy may be similar to those with CM due to the similar symptoms found in the disorders. Overall, it appears that in elective surgery, disability and physical limitations caused by the disorder are the most important factors in patient decision-making.

Purpose

This study evaluated factors that affect patient decision-making when patients had a choice to undergo elective surgery for CM (a risky but potentially definitive cure). The present study will add to the literature on the factors that influence patient decision-making for elective surgery and will be the first study to look at factors affecting decision-making regarding treatment for patients with CM.

Method

Participants

Participants were part of a larger online study and were recruited from the Angioma Alliance Patient Registry. Angioma Alliance is an organisation working to advance scientific understanding of CM, and which provides information and support to individuals and families affected by this disorder (Angioma Alliance, 2010). The Angioma Alliance Patient Registry is a registry of individuals diagnosed with CM who have indicated willingness to be contacted for research studies. At the time that this study was completed, approximately 750 individuals were registered in the Angioma Alliance Patient Registry.

Registered participants were emailed a link to the survey. A total of 272 individuals completed the online survey, for a response rate of approximately 36%. Participants were selected for this study if they answered 'yes' to the question 'Were you given a choice to have surgery' ($n = 134$). Participants' ages ranged from 25–77 years, with the average age being 44.9. The majority of participants identified as female (73.1%), while 26.9% identified as male. Most participants reported that they live in the United States of America (72.8%), in the United Kingdom (8.9%) or in Canada (3%). The remaining participants were from 13 other countries: Australia, Belgium, China, Indonesia, New Zealand, Singapore, Croatia, Italy, Lithuania, Netherlands, Denmark, Colombia and Brazil. Participants reported on their relationship status, such that 65.4% indicated they were married or equivalent, 7.5% single, 12.8% in a long-term relationship, and 8.3% divorced, while the remaining participants reported either being separated, widowed or dating.

Individuals from this sample were highly educated, with 75.2% reporting they had an associate degree, a Bachelor's degree, or a graduate or professional degree. A total of 56% of respondents indicated they were employed for pay, 6.7% were out of work, 22.4% reported they were unable to work, while the remaining participants were either retired, homemakers or students. The vast majority of the sample identified as being white (91.6%). Most of the sample indicated that they have health insurance (89.1%), and 78.0% of these reported that their insurance covers all needed or recommended treatment for their CM. Additionally, 81.3% of participants indicated that they live within 300 miles of a vascular neurosurgeon experienced in treating CM.

Measures

Participants were first prompted with the question 'Were you given a choice to have surgery'. If yes, they were asked to rate the importance of six factors in their decision-making. The ratings were on a four-point scale ranging from not important to most important. The factors that were chosen for this study came from a review of topics discussed in the Angioma Alliance patient forum, and elsewhere on the Angioma Alliance website.

Results

A total of 75 participants (56%) reported having had surgery one or more times (62 have had surgery once, seven twice, one three times and four participants have had surgery four times). Of these, 56% reported that their surgery and recovery went as they expected them to. Among patients who had had surgery, 64% indicated that they thought they were better off after surgery than before surgery, 16% said they were not and 20% indicated that they were not sure. For the most part, participants also reported that if they had known in advance what surgery and recovery would be like for them, they would still have had it (77.3%). Compared with the symptoms people had presurgery, 30.1% of participants indicated that some symptoms got worse and some got better, 13.7% said their symptoms got worse or stayed worse, 11% said that symptoms got worse at first then improved to same or better, 8.2% stated that their symptoms stayed the same, and 37% said their symptoms improved.

A repeated measures ANOVA with a between subjects variable found a significant main effect of the within-subjects variable of decision-making factor, $F(5) = 41.11$, $p < 0.001$ indicating that a significant difference exists between the factors. No differences were found for the between subjects variable (whether or not the participant chose to have surgery, $F(1) = 0.42$, $p = 0.52$), and there was no significant interaction found for the between and within variables, $F(1) = 1.02$, $p = 0.40$. Therefore, participants reported the same factors to be important in their decision-making, regardless of whether or not they chose to undergo surgery.

Paired samples *t*-tests were conducted as *post hoc* tests to compare factors against one another to determine which factors are considered more important in making a decision about having surgery. As 15 separate comparisons were conducted, a Bonferroni correction was used so that only comparisons with a *p*-value of <0.003 were considered significant. This correction method is conservative, but did not

change the results when compared with conducting the *post hoc* tests with no correction. Table 1 displays the means and standard deviations of each factor and reports on the significant differences between the factors.

The first set of analyses investigated the perceived importance of the doctor's opinion compared to all the other factors. There was a significant difference in the perceived importance of the doctor's opinion and having the means to pay for surgery in deciding whether or not to have surgery; $t(122) = 9.08$, $p < 0.001$. There was also a significant difference between the doctor's opinion and the availability of support during recovery in deciding whether or not to have surgery; $t(120) = 8.69$, $p < 0.001$. There was no significant difference between the doctor's opinion and the other factors: disabling symptoms, $t(122) = 0.18$, $p = 0.86$; fear of symptoms getting worse or developing new symptoms, $t(128) = -1.18$, $p = 0.24$; and availability of an expert surgeon, $t(125) = -0.33$, $p = 0.74$. These results suggest that doctor's opinion is more important in decision-making regarding whether or not to undergo surgery than is the means to pay for surgery or the availability of support during recovery (Table 2).

The second set of analyses compared the importance of disabling symptoms in making a decision about whether or not to have surgery and the remaining four factors. There were significant differences between disabling symptoms and two factors: means to pay for surgery, $t(118) = 8.25$, $p < 0.001$; and availability of support during recovery, $t(115) = 6.50$, $p < 0.001$. The importance of disabling symptoms was not significantly different from the remaining two factors in decision-making: fear of symptoms getting worse or developing new symptoms, $t(120) = -1.42$,

$p = 0.16$; and availability of an expert surgeon, $t(121) = -0.68$, $p = 0.50$. These results suggest that disabling symptoms are more important in decision-making regarding surgery than is the means to pay for surgery or the availability of support during recovery.

Fear of symptoms getting worse or developing new symptoms was then compared to the rest of the factors in its importance for decision-making in regard to whether or not to receive surgery. There were significant differences between fear of symptoms getting worse and two factors: means to pay for surgery, $t(121) = 10.30$, $p < 0.001$; and availability of support during recovery, $t(120) = 8.81$, $p < 0.001$. There was not a significant difference between fear of symptoms getting worse and availability of an expert surgeon in decision-making, $t(125) = 0.85$, $p = 0.40$. The results suggest that fear of symptoms getting worse or developing new symptoms is more important in decision-making than the means to pay for surgery or the availability of support during recovery.

The last set of analyses investigated the remaining relationships between the factors affecting decision-making regarding surgery. There was a significant difference between availability of an expert surgeon and having the means to pay for surgery (through insurance or otherwise), $t(120) = 9.90$, $p < 0.001$. There was also a significant difference between availability of an expert surgeon and availability of support during recovery, $t(118) = 8.69$, $p < 0.001$. Lastly, analyses revealed a significant difference between having the means to pay for surgery and the availability of support during recovery, $t(115) = -3.55$, $p < 0.01$. These results suggest that the availability of an expert surgeon is more important in decision-making than is the means to pay for surgery or the availability of support during recovery. Additionally, the availability of social support during recovery appears to be more important than the means to pay for surgery when deciding whether or not to have surgery.

Table 1 Means and standard deviations of factors related to decision-making about surgery

Factor	n	Mean	Standard Deviation
1. Doctor's opinion	132	3.34 ^{5,6}	0.66
2. Disabling symptoms	124	3.32 ^{5,6}	0.81
3. Fear of symptoms getting worse or developing new symptoms	131	3.44 ^{5,6}	0.71
4. Availability of an expert surgeon	128	3.38 ^{5,6}	0.79
5. Means to pay for surgery (through insurance or otherwise)	124	2.27 ^{1,2,3,4,6}	1.17
6. Availability of support during recovery	122	2.53 ^{1,2,3,4,5}	1.01

Superscripts indicate significant differences between factors.

Discussion

Results indicated that a variety of factors affect the decision-making process of individuals who have a choice to undergo surgery to remove CM. In the present study, factors that were rated most important for an individual's decision-making included doctor's opinion regarding surgery, presence of disabling symptoms, fear of symptoms getting worse or developing new symptoms, and availability of an expert surgeon. Results indicated that these factors did not significantly differ in importance, but were rated as more important than having social support during recovery

Table 2 Paired sample *t*-test comparisons of surgery decision-making factors

Factor	Doctor's opinion	Means to pay for surgery	Availability of social support	Disabling symptoms	Fear of symptoms getting worse or developing new symptoms
Doctor's opinion	X				
Means to pay for surgery	$t = 9.08, p < 0.01$	X			
Availability of social support	$t = 8.69, p < 0.01$	$t = -3.55, p < 0.01$	X		
Disabling symptoms	$t = 0.18, p = 0.86$	$t = 8.25, p < 0.01$	$t = 6.50, p < 0.01$	X	
Fear of symptoms getting worse or developing new symptoms	$t = -1.18, p = 0.24$	$t = 10.30, p < 0.01$	$t = 8.81, p < 0.01$	$t = -1.42, p = 0.16$	X
Availability of an expert surgeon	$t = -0.33, p = 0.74$	$t = 9.90, p < 0.01$	$t = 8.69, p < 0.01$	$t = -0.68, p = 0.50$	$t = 0.85, p = 0.40$

or having the means to pay for surgery. Additionally, having social support during recovery was rated as significantly more important than having the means to pay for surgery.

The results have considerable implications for individuals who have a choice to undergo an elective surgery for a potentially disabling condition. Results of this study are consistent with those found across many types of both elective surgeries and surgeries for life-threatening conditions. Specifically, participants rated doctor's opinion as an important factor in their decision-making. This was also found in gynaecological patients (Uskul *et al.* 2003), epilepsy patients (Anderson *et al.* 2013), and cancer patients (Sidana *et al.* 2012, Jorgensen *et al.* 2013). Similar to the participants of this study, patients struggling with cancer valued the doctor's recommendation (Sidana *et al.* 2012) regardless of the treatment chosen by the patient. Participants in this study considered the same factors important in their decision-making process regardless of whether or not they decided to have surgery. This suggests that although the decision is often ultimately left up to the patient, patients weight their doctors' opinions heavily. Thus, doctors must be mindful of how they frame recommendations, and must be careful to provide sufficient information about surgery to their patients.

Results indicated that disabling symptoms, and fear of symptoms getting worse or developing new symptoms were also important to patients in choosing whether or not to undergo surgery. Previous studies in elective gynaecological surgeries have also found that the presence of disabling symptoms which decrease quality of life are an important factor in decision-making (Uskul *et al.*, 2008), and deformity and scoliosis patients rated functional limitations resulting from their disorder as an important factor in decision-making (Pekmezci *et al.* 2009, Quon *et al.* 2011). Disability and physical limitations appear to be important factors across elective surgery decision-making. In this sam-

ple, among those who had had surgery, only 37% indicated unequivocally that symptoms improved. Realistic information and expectations about potential for improvement or harm, and adequate information about risks from surgery is crucial in weighing this factor appropriately.

Previous research in surgery decision-making has found mixed results about the impact of social support during recovery. Research with scoliosis patients has found that patients will make their decision regardless of support from family and friends (Quon *et al.* 2011). Conversely, women who have a choice to undergo hysterectomy say that family opinions are important in decision-making (Uskul *et al.*, 2008). The present study found that social support during recovery was not an important factor for CM patients compared to other factors. The differences found in the literature may be due to the type of symptoms and result of surgery. Patients who seek surgery for CM or scoliosis may see surgery as the only way for disabling symptoms to be treated, and may thus make this decision independent of availability of social support. On the other hand, this sample reported generally high socioeconomic status (SES), and availability of social support may be less important when resource availability is generally high. Further research is required to determine whether disease/disorder characteristics or other factors contribute more to the impact of social support on surgery decision-making.

The means to pay for surgery was found to be the least important factor in decision-making. This result could also be due to the specific sample as the majority of participants were highly educated, had a high income, and had health insurance. Thus, for this sample, means to pay for surgery may have been less of a concern than it would be for a lower SES sample. However, the results are also consistent with decision-making research for cancer patients, where the means to pay for surgery is not of high importance (Jorgensen *et al.* 2013). Again, further research is needed to

determine when or whether this factor is relevant to surgery decision-making.

One of the most prominent models of decision-making is shared decision-making, which focuses on a partnership between the health provider and the patient (Makoul & Clayman 2006). In the case of surgery for CM patients, the decision is often left up to the patient, indicating a patient-based decision model. In their systematic review, Makoul and Clayman (2006) indicated that shared decision-making occurs on a continuum between the physician's opinion and the patient's, and results of the current study indicate that the physician's opinion is an important consideration in patients' decision-making. A recent study found that most patients (62.5%) undergoing invasive medical procedures preferred shared decision-making, while only 15.5% preferred patient-based decision-making (Mazur *et al.* 2005). Regardless of the role patients preferred to take in decision-making, they often rated the doctor's opinion of whether or not to undergo the procedure to be of high importance (Mazur *et al.* 2005).

Limitations

A limitation to the generalisation of these findings is that the sample was predominantly female (73.1%), highly educated, and white (91.6%), and is thus not representative of patients with CM, or the population generally. Additionally, the vast majority of participants (89.1%) had health insurance, of which 78.0% reported that the insurance covers all required treatment for their CM. Therefore, this research does not address the decision-making process of vulnerable populations such as those that are of low socioeconomic status or uninsured. A sample of lower socioeconomic status may consider other factors more important in deciding whether or not to undergo surgery, such as the means to pay for surgery. Additionally, the availability of social support post-surgery may be important in other samples, due to lower SES or cultural differences such as a more collectivist approach to decisions and healthcare (Lin *et al.* 2013).

All participants had previously indicated a willingness to be contacted about research studies related to CM, and their decision-making process may differ from that of individuals who chose not to be conducted regarding research. Given these discrepancies between this study's sample and the general population, results should be interpreted with

caution. A case series may provide a more representative picture of factors affecting decision-making in CM patients.

The current research is limited by the quantitative approach. Future research should employ a qualitative design to explore other factors and thought processes that influence decision-making about surgery in medical patients. The results are further limited by only providing insight into decision-making from a patient perspective. Given the influence of healthcare providers, caregivers, and family members, future studies would benefit from including a variety of perspectives into the exploration of decision-making regarding surgery in patients with CM.

Conclusion

It appears that doctor's opinion regarding surgery, presence of disabling symptoms, fear of symptoms getting worse or developing new symptoms, and availability of an expert surgeon are important factors in surgery decision-making for individuals with CM. These factors were found to be more important than social support during recovery and the means to pay for surgery. The results were similar to those found with other medical conditions requiring elective surgery.

Relevance to clinical practice

This study provides invaluable information of patient perspectives in elective surgery decision-making. By understanding the complex factors that affect decision-making in CM, healthcare professionals may be able to better communicate and support patients in their elective surgery decision-making.

Contributions

Study design and data collection were completed by BK. Analysis and manuscript preparation were completed by BK, CM, and AT.

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