

Patient Experiences with Cavernous Malformation

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This study was an online survey of adults with a confirmed diagnosis of cavernous malformation. Research participants answered questions about many different aspects of their lives, including physical and mental health, experiences with the medical system and medical providers, ability/disability in a variety of domains, history of stressful/traumatic experiences, and aspects of the social environment like social support and work. A donation of \$5 CAD was made to Angioma Alliance (Angioma Alliance Canada for Canadian participants) for each eligible person who participated in the study. This project was approved on ethical grounds by the University of Regina Research Ethics Board. Below are some of our initial findings from this research study. As we continue to analyze data and present the findings at conferences and in academic papers, we will add links to those papers at <http://uregina.ca/~schtlab/pages/about/aboutComplete.html>.

A total of 272 people participated in the survey. There were participants from around the world, with most being from the United States ($n = 187$, 68.8%), United Kingdom ($n = 27$, 9.9%), and Canada ($n = 23$, 8.5%), and the remaining participants coming from 22 other countries including Australia, Belgium, Brazil, China, Croatia, Denmark, Gibraltar, Indonesia, Ireland, Italy, Japan, Latvia, Lithuania, Mexico, Netherlands, New Zealand, Norway, Singapore, South Africa, Sweden, Thailand, and Ukraine.

73% of the participants were female ($n = 199$), 25% were male ($n = 68$), and 2% did specify their gender.

Participants ranged in age from 18 years old to 77 years old, and the average age was 44.35 ($SD = 11.71$).

Most participants were married or in a long-term relationship ($n = 209$, 76.8%), and smaller numbers were single or dating ($n = 34$, 12.5%), divorced or separated ($n = 23$, 8.5%), widowed ($n = 3$, 1.1%), or did not specify ($n = 3$, 1.1%).

A vast majority of participants were White (87.1%), with a small number of participants identifying as Asian (2.2%), Native Hawaiian or Other Pacific Islander (<1%), American Indian, Alaska Native, or Aboriginal (<1%), Black or African American (<1%). The remainder selected "other," with many of these participants indicating they were Latino or mixed-race (2.9%), or did not specify (5.9%). A total of 10.7% of participants identified as Hispanic or Latino.

With regard to living situation, 10.7% indicated that they lived alone, 63.6% lived with a spouse or partner, and 2.9% reported living with roommates. A relatively large proportion of participants reported living with children (34.2%) or other family members (12.5%), and none indicated that they lived in long-term care or assisted living. Percentages here do not add up to 100% because participants could select more than one response to this question.

The median household income in this sample was \$60,000-\$69,000 per year (ranging from less than \$10,000 to more than \$150,000), and the average number of people supported on that income was 2.79 ($SD = 1.32$).

Fully one third of the sample reported that they had experienced a significant decrease in income, related to factors such as having to change jobs or stop working as a result of disability. Individuals who indicated that they were unable to work due to disability were significantly more likely to have experienced a substantial decrease in income ($\chi^2(1) = 47.54, p < .001$).

More than half of participants ($n = 151, 56\%$) indicated that they had worked for pay in the past month, and about one in five ($n = 55, 20.2\%$) reported that they were unable to work due to disability. Other employment activities reported by participants included being unemployed/out of work ($n = 17, 6.3\%$), on temporary leave (e.g., medical, parental) with plans to return to work ($n = 9, 3.3\%$), homemaker ($n = 19, 7\%$), student ($n = 13, 4.8\%$), and retired ($n = 17, 6.3\%$). Percentages here do not add up to 100% because participants could select more than one response to this question, though most selected only one.

Participants in this sample were highly educated, with 25.7% indicating that they held a graduate or professional degree, 27.2% bachelor's degree or equivalent, 17.3% associate or technical degree, 16.9% some college/postsecondary credit with no degree, 5.5% high school diploma or equivalent, 1.5% less than high school diploma, and 5.9% did not specify level of education completed.

Most common reasons for seeking medical care that resulted in the initial diagnosis of cavernous malformation were focal neurological symptoms (56.3%), headache (36%), seizure (21.7%), incidental finding from an unrelated MRI (10.3%), genetic or MRI diagnosis due to having an affected family member (7.4%), and other symptoms (14%). Percentages here do not add up to 100% because participants could select more than one response to this question.

Just over half (52.9%) of the sample indicated that they have a single cavernous malformation, while 37.1% reported that they know they have multiple lesions. Brainstem lesions were reported by 43% of participants, and 34.9% reported that they had one or more lesions in other "eloquent" brain areas, where a bleed is very likely to cause symptoms. Spinal cord lesions were relatively rare in this sample (8.1%).

Most participants (84.9%) indicated that they have some form of public or private health insurance. Of these, 22.6% reported that their insurance does not cover all needed or recommended treatment for cavernous malformation. When adding this percentage to the proportion of the sample that is uninsured, approximately one third of the sample indicated not having adequate coverage for treatment of cavernous malformation.

Approximately half of individuals completing the survey (49.4%) reported that they had been misdiagnosed with another condition prior to receiving a correct diagnosis of cavernous malformation. 42.3% reported that they had at some point experienced a delay in medical care for cavernous malformation, due to factors such as wrong diagnosis, a provider being unavailable, or financial or medical system barriers. Of these, approximately two-thirds (64.6%) indicated that they believe this delay in care resulted in new or worsening symptoms.

Approximately one third of participants (33.5%) reported that they had had surgery to remove one or more cavernous malformations. Of these individuals, 43.8% reported that surgery and recovery did not go as they expected it to. Among individuals who had had surgery, factors that were reported to contribute to a difference between expectations and actual experience of surgery and recovery included the following: not being informed that the outcome that occurred was a possibility (12.1%), being told that the outcome that occurred was unlikely (11%), being told that the outcome was possible, but not expecting it to occur (9.9%), the information given about possible outcomes was difficult to understand (2.2%), doctors were uninformed or provided misinformation (4.4%), information was provided about surgery but not recovery (3.3%), general lack of information (2.2%), and other (4.4%). Percentages are of all individuals who had had surgery, and individuals could select more than one response to this question.

Among those who had had surgery, 66.3% reported that all things considered they believe that they are better off after surgery than before surgery, and 33.7% report that they are not better off or are unsure. When asked "All things considered, if you had known in advance what surgery and recovery would be like for you, would you still have had it?," 78.9% of participants reported that they would still have surgery, and 21.1% indicated that they would not or are unsure.

One criterion for determining whether an experience qualifies as traumatic is whether it caused actual or threatened death or serious injury. A significant number of participants in this survey reported that they believe their cavernous malformation(s) has/have been a threat to life (37.1%), caused threat of serious injury (39%), and/or caused actual serious injury (21.3%).

While a majority of participants in this study rate their health as good, very good, or excellent (71.7%), a substantial portion (28.3%) rate their health as poor or fair.