

Key Points

- James Meeker and his associates used the Conquer Chiari Patient Registry Database to measure how CM symptoms affect daily living tasks and restrict various forms of exercise.
- The Conquer Chiari Patient Registry is a secure patient database which allows patients to record and submit their detailed Chiari experience online.
- Some of the most popular daily activities which are affected by Chiari symptoms include: housecleaning, driving, shopping, walking up and down stairs, and washing laundry. Those with significant CM symptoms also experience a decrease in self-sufficiency.
- Many Chiari patients expressed that athletic hobbies were harder to enjoy with their current or worsening symptoms.
- In the future, Meeker et al. declare that researchers should attempt to determine the impact of a patient's psychological and social aspects associated with Chiari and the struggle to obtain/maintain needed medical services.

Source

[The impact of Chiari malformation on daily activities: A report from the national Conquer Chiari Patient Registry database.](#)

Meeker J, Amerine J, Kropp D, Chyatte M, Fischbein R. *Disabil Health J.* 2015 Jan 31. pii: S1936-6574(15)00004-7. doi: 10.1016/j.dhjo.2015.01.003. [Epub ahead of print]

Understanding How Chiari Symptoms Affect Daily Activity

March 2015 - After becoming diagnosed with a Chiari malformation (CM), most patients are faced with a wide array of short-term and long-term health uncertainties which affect their everyday lives. Although some individuals with symptomatic Chiari are not severely impaired, there still may be concerns involving their capabilities in the future.

Focused on measuring the influence CM has on daily living activities, five medical research scholars analyzed patient information provided by the **Conquer Chiari Patient Registry Database**, originally designed by Rick Labuda, the Executive Director of Conquer Chiari. The team's overall goal was to try and understand how symptoms alter the way individuals with CM manage day-to-day chores as well as exercise.

Conquer Chiari awarded James Meeker and his colleagues a grant to pursue their self-assessed patient study utilizing the database. This secure, online patient database was created to investigate multiple aspects of living with Chiari; however, for this study, James Meeker et al. focused mainly on patient demographics, patient-assessed CM information, and the overall impact Chiari has on quality of life.

A considerable amount of data, collected between August 2012 and April 2014, was utilized by Meeker and his team to understand the daily struggles of Chiari patients. Although parents, guardians, or caretakers of Chiari patients under the age of eighteen are allowed to submit information into the database, their data was not included in this patient-based study. Out of 957 original cases, 798 were included and evaluated as reliable, first-hand sources.

Within the patient population, 693 individuals were female and 64 were male, averaging 41 years of age, and most claimed that they started having CM symptoms around the age of 21. CM-1 was the most common diagnosis recorded (81.8%) while CM-2, CM-3, and CM-4 combined affected around 8% of patients. When compared to other CM demographics, this basic information appears to reflect the average adult Chiari population relatively well.

Meeker et al. then explored information related to employment—an area that is not always discussed or studied in detail. 718 patients reported on their ability or inability to work: 331 held jobs outside of their house, 163 were unable to work, 65 were students, 58 were unemployed, 54 were homemakers, 25 worked from home, 16 were retired, and 6 were given worker's compensation. Respondents were also asked about their employment status as a full-time or part-time employee, but many chose not to answer this section of the database because it was not relevant to their individual situations. However, among those who chose to disclose their past or present work information, 118 participants stated that after they were diagnosed with Chiari they encountered an average decrease of \$19,900 in their annual monetary income.

The research scholars moved on to explore the impact of Chiari symptoms on daily activities such as self-care, household chores, and other routine tasks. Before reporting their difficulties, patients were asked to rank their symptom severity as minor, moderate, or severe. Altogether, the three distinct groups reported that housecleaning was the most difficult day-to-day chore followed by driving, shopping, and walking up and down stairs. Individuals with minor CM symptoms were not as affected as those with moderate or severe Chiari.

Other obstacles faced by those with an increase of symptoms include: doing laundry, operating a computer, and preparing food. Naturally, patients with significant CM-related deficits also have problems with self-care (e.g. personal hygiene, getting dressed, going to the bathroom unassisted).

Considering that the development of Chiari symptomatology most often causes a decrease in self-sufficiency, Meeker et al. reported that many respondents shared a dwelling with one or more individuals (614) while others lived alone (66). This valuable data demonstrates how Chiari symptoms negatively impact patients' abilities to accomplish necessary chores and activities associated with everyday living.

Additionally, Meeker et al. explored the influence that Chiari has on athletic interests and hobbies. Those with minor and moderate symptoms, who chose to participate in this section, expressed that they could no longer enjoy forms of exercise such as walking/hiking, running, yoga, and bike riding. Severe symptom sufferers could also not participate in those types of activities in addition to swimming, weight training, dancing, aerobics, and contact sports. Although minor and moderate grade CM patients had lower percentages of physical inability, the study's data determines that Chiari can inhibit many important forms of exercise.

By examining CMs impact on routine tasks and athletic activities, Meeker and his colleagues have presented considerable data from the database which proves that Chiari symptoms significantly disrupt the lifestyles of countless patients. Since CM affects everyone differently, the next step may be to attempt to determine how specific symptoms impact certain areas of a patient's life. To close, the researchers claim that investigating the psychological and social circumstances associated with Chiari as well as the struggle to obtain/maintain needed medical services should be evaluated in the near future.

Author's Note: To find out more about the Conquer Chiari Patient Registry, take a look at our [Patient Registry Information Page](#) which outlines a few general questions about the survey. If you would like to submit information to assist future studies, please visit the Conquer Chiari Patient Registry Database login page: chiari.remedymd.com/ Participants may choose to submit as much or as little as they like—however, partially complete surveys may not end up being utilized by specialists depending on the type of research being tested. Your assistance can greatly benefit future Chiari research!



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Ms. Eubanks is a professional writing and researching scholar from Purdue University Northwest. After being diagnosed with a Chiari I Malformation in 2011, she quickly decided that being conquered was not an option—she was committed to fight and pursue a budding love of healthcare/medical writing. Spreading awareness and hope to others battling Chiari is her largest motivator alongside educating others who have not heard about the condition. Reporting for Ideas in Motion Media and tutoring at the Writing Center (Purdue University North Central) has been immensely beneficial to her success as well as all the remarkable individuals who helped her become the composer and analyst she is today.

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