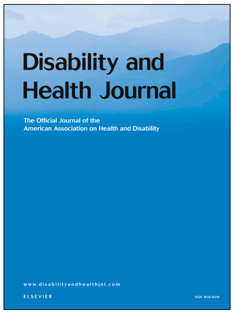

The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

James Meeker, MA, Jenna Amerine, MPH, CHES, Denise Kropp, BS, CCRP,
Michelle Chyatte, DrPH, MPH, Rebecca Fischbein, PhD

PII: S1936-6574(15)00004-7
DOI: 10.1016/j.dhjo.2015.01.003
Reference: DHJO 369

To appear in: *Disability and Health Journal*

Received Date: 19 August 2014
Revised Date: 9 December 2014
Accepted Date: 19 January 2015

Please cite this article as: Meeker J, Amerine J, Kropp D, Chyatte M, Fischbein R, The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database, *Disability and Health Journal* (2015), doi: 10.1016/j.dhjo.2015.01.003.

Title: The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

Authors:

James Meeker, MA, Graduate Assistant, Department of Family and Community Medicine, Northeast Ohio Medical University

Address: 4209 St. Rt. 44, PO Box 95 Rootstown, Ohio 44272

Phone: 330-325-6582

Email: jmeeker@neomed.edu

Jenna Amerine, MPH, CHES, Research Specialist, Department of Family and Community Medicine, Northeast Ohio Medical University

Corresponding Author

Address: 4209 St. Rt. 44, PO Box 95 Rootstown, Ohio 44272

Phone: 330-503-3738

Email: jamerine@neomed.edu

Denise Kropp, BS, CCRP, Research Associate, Department of Family and Community Medicine, Northeast Ohio Medical University

Address: 4209 St. Rt. 44, PO Box 95 Rootstown, Ohio 44272

Phone: 330-325-6171

Email: djkropp@neomed.edu

Michelle Chyatte, DrPH, MPH, Assistant Professor and Research Coordinator, Department of Family and Community Medicine, Northeast Ohio Medical University

Address: 4209 St. Rt. 44, PO Box 95 Rootstown, Ohio 44272

Phone: 330-325-6166

Email: mchyatte@neomed.edu

Rebecca Fischbein, PhD, Research Coordinator and Assistant Professor, Department of Family and Community Medicine, Northeast Ohio Medical University

Address: 4209 St. Rt. 44, PO Box 95 Rootstown, Ohio 44272

Phone: 330-325-6361

Email: rfischbein@neomed.edu

Keywords: Arnold-Chiari Malformation, quality of life, daily living, physical activities, recreational activities

Financial Support: This research was funded by a grant from the *Conquer Chiari Research Foundation*.

Acknowledgements: We wish to thank the patients and caregivers of patients with CM who provided information on the registry. We also wish to thank the Conquer Chiari Research Foundation and especially Rick Labuda who designed the patient registry and recruited CM patient participants. Without his efforts this research would not be possible.

Conflict(s) of Interest: None.

Abstract Word Count: 177

Manuscript Word Count: 3,207

Number of References: 15

Number of Tables: 3

The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

ABSTRACT

Background: Chiari Malformation (CM) is characterized by herniation of the cerebellar tonsils into the cervical spine. While ample literature on CM exists for clinical and procedural aspects of the disease, few studies have measured the impact CM has on daily activities.

Objective: The objective of this study was to measure the impact that CM has on daily living activities.

Methods: Data was analyzed from 798 CM patients gathered by the national Conquer Chiari Patient Registry database.

Results: Results indicate CM is associated with negative impact on daily living and physical activities for patients, even those exhibiting mild symptoms. Participants with severe symptoms experience the greatest deficit with regards to daily living such as difficulty walking, driving, house cleaning and food preparation.

Conclusions: As 96.1% of CM patients report impact in one or more areas of daily living, CM is classified as a disability according to 42 U.S. CODE § 12101 (Americans with Disabilities Act). The degree of self-reported CM symptom severity is strongly related to the frequency and extent of limitations in both physical and daily activities.

INTRODUCTION

First identified in the late Nineteenth Century, Chiari Malformations (CM) are congenital conditions in which the cerebellar tonsils have herniated into the cervical spine[1]. There are four sub-types of CM recognized: Type I, the most common type of CM, characterized by tonsil herniation greater than five millimeters past the foramen magnum, Type II, consisting of herniation of the brain stem and associated ventricles through the foramen magnum, Type III, typified by occipital encephalocoele and intracranial defects, and Type IV, associated with hypoplasia or cerebellar aplasia[2]. Clinical manifestations of CM symptoms include: neck pain, occipital and suboccipital headache, generalized body weakness, difficulty swallowing, sleep apnea, fatigue, vertigo, and ocular dysfunction[1-4]. According to prior research, headaches have been noted as the most common symptom associated with CM negatively impacting one's quality of life[3,5]. Estimates of CM prevalence among the population vary, with early estimates based on autopsy data predicting a prevalence ratio of 1/18,000[6] to more current estimates as high as 1/100 based on analysis of magnetic resonance imaging (MRI) of the general population[7]. Prior research[8-9] suggests more women are affected by CM related disorders than men with typical symptom onset between 25 to 45 years of age[2].

Currently the focus on CM research resides primarily on detection, classification and surgical treatment of the disorder[2,8-10]. While studies have been conducted examining pre and post-operative quality of life among CM patients, notably Mueller and Oro[1] and Sixt, Reither, Will, et al.[11], the primary focus has been largely confined to detailing symptom typology and severity. Furthermore, prior CM research[1,11] examining quality of life has been conducted using only limited size datasets. Suggesting the possibility that CM is a disability, Jenkinson et al.[12] found that even with intervention, the prognosis for independent living among patient with CM was poor. Further indicating the severity of the disorder, Sixt[11], reports that CM symptoms generally result in a lower quality of life for patients akin to other chronic diseases including cancer, diabetes, and paresis. Despite research on the range of CM symptoms, gaps exist in understanding how these symptoms influence the patients' ability to perform and enjoy daily activities. Consequently, the current research explores the impact of CM on patients' daily living and recreational activities.

METHODS

This study quantitatively analyzed data collected and managed by the Conquer Chiari Foundation, a non-profit 501 (c)(3) organization dedicated to raising awareness and researching CM and syringomyelia. This study was approved by the Institutional Review Boards of the Northeast Ohio Medical University and The University of Akron.

Sampling strategy

The Conquer Chiari Foundation has created a secure, online patient registry database to serve as a data collection tool—the *Conquer Chiari Patient Registry* (CCPR). The CCPR allows patients with CM to voluntarily enter health-related data to the database. Prior to accessing the registry, subjects must grant consent indicating their understanding that information provided will be used for research purposes. All patient data provided to the CCPR is voluntary and de-identified. Patients are recruited to participate in the CCPR through the Conquer Chiari website (conquerchiari.org) and the Conquer Chiari Research Center website (chiari-research.org). There is no compensation for participants volunteering to participate in the CCPR.

Patients eligible for inclusion into the CCPR database are persons aged eighteen or older that have been diagnosed withCM, or have magnetic resonance imaging (MRI) indicating cerebellar herniation in excess of 0.05 millimeters. Parents and legal guardians may enter data for CM patients under the age of eighteen. Similarly, otherwise eligible patients physically incapable of entering data can use the services of a caretaker to enter information into the database. All inclusionary or exclusionary data is provided by patients when creating an account for the CCPR and is not verified by the Conquer Chiari Foundation.

The CCPR is a "live" database, meaning that new patients are added to the registry almost daily. However, due to the dynamic nature of the CCPR, only subjects creating a profile between August 2012, when the CCPR went online, and April 2014 were included in this analysis.

Excluded cases

As of April, 2014 there were a total of 957 cases in the CCPR database reporting CM diagnosis or MRI results indicating cerebellar herniation greater than 5 millimeters. A number of cases had to be excluded based upon two criteria: (1) survey completed by someone other than the patient, and (2) being under the age of 18. There were 159 cases in which an individual other than the patient was indicated as completing the survey. The terms and conditions of the CCPR allows parents and caregivers to provide data for patients under the age of 18 or otherwise incapable of completing an online survey. However, such responses are inadequate for meeting the criterion of self-assessment of symptom severity and difficulty performing daily activities. Therefore, cases indicating someone other than the patient completing the survey were omitted from this study. Additionally, cases in which the patient was under the age of 18 were omitted from the analysis. Based on the above criteria a total of 798 valid cases were analyzed.

Measures

All measurements in this study are taken from self-reported participant data collected by the CCPR database. The CCPR database consists of fifteen content areas. However, this report focuses only on data gathered in the quality of life impact section, as well as the patient CM overview and patient information/demographics sections.

There were three categories of measurements: (1) self-assessment of severity of CM symptoms, (2) patient demographics, and (3) self-reported assessments of patient functionality in daily activities. To assess the severity of symptoms patients were asked if CM has had a negative impact on their ability to engage in physical activities. If the patient responded “yes” they were asked to rate the severity of CM symptoms in ordinal scale ranging from: minor symptoms, moderate symptoms, and severe symptoms.

Patient demographics collected were: age, age of Chiari symptom onset, gender, race and ethnicity, type of CM, employment status, domestic status, and highest level of education attained.

Daily living functionality was assessed in two areas: (1) activities of daily living (ADL) and instrumental activities of daily living (IADL), and (2) physical and recreational activities. Subjects were asked to report if CM symptoms negatively impacted their ability to engage in daily activities on an ongoing basis. Patients were instructed to only indicate negative impact if the condition was not related to surgical treatments of CM. Subjects were not asked to rate the degree of difficulty in each area, only whether CM symptoms had a negative impact.

ADLs included everyday functions essential for self-care such as bathing/personal hygiene or getting dressed. IADLs included everyday functions necessary to living such as housecleaning or using a computer. Physical and recreational items included actions such as participating in sports, exercise, or dancing. Additionally, participants were asked if there were physical activities they can no longer engage in or enjoy due to CM symptoms. Patients affirming inability to perform recreational activities due to CM symptoms were asked to specify the top three activities in an open text, qualitative dialogue box.

Analysis

Primary analysis consisted of two parts: (1) demographic results, and (2) impact of CM on daily activities. All statistical analysis was conducted using SPSS version 21 (IBM/SPSS, Inc., Chicago, Illinois). Descriptive statistics were generated for demographic variables of the population. A paired t-test was also conducted to look at the loss of income due to CM. Analysis of daily activities consisted of two areas, living activities and recreational activities. Participants were grouped based on their self-reported CM symptom severity into three categories, minor, moderate, and severe. Statistical analyses were performed on each of the question areas within living and recreational activities. In both cases a Pearson Chi-Square test was performed as a measure of the impact of CM on daily activities based on the self-reported levels of symptom severity.

RESULTS

Participants in this sample population were predominately female (86.8%). The average respondent age was 40.8 years. First onset of CM symptoms was 20.5 years of age. The vast majority of persons in the database were indicated to be white or white-Hispanic (90.0%). The next largest racial and ethnic category reported were American Indian (3.9%). Only 2.1% of respondents identified as black or African American or black Hispanic. Asian, which contains Asian Indian, Chinese, Fillipino, Japanese, Korean, and Vietnamese, comprised 1.0% of the sample population.

Type I was the most commonly identified CM typology, representing 81.8% of the population. Only 5.4% of the population exhibited CM type II, with 2.0% of respondents indicating another type of CM and 10.8% either not reporting type or indicating type was unknown.

Generally, most respondents were employed outside the home. In this study 41.5% of subjects reported working outside their home. More than one-in-five subjects indicated they were unable to work due to disability—20.4%. Many of the respondents were full-time students, comprising 8.1% of the sample. Homemakers comprised 6.8% of the population, 3.1% worked at home, and 2.0% were retired. Consistent with national rates[13], 8.1% of subjects reported being out of work at the time they completed the CCPR survey. Only 18.3% of the sample population reported working full-time and 6.4% were employed part-time However, as many participants did not report their employment status (75.3%), these measures may not accurately reflect the general population of patients with CM. Annual salaries before and after a diagnosis of CM were reported by 118 participants; a paired t-test indicated that on average they experienced a $19,900 ($p$<.0001) reduction in annual salary after diagnosis. Participants that responded whether CM had a negative impact on overall financial position 66% reported affirmatively.

The majority of the patients with CM reported living with a spouse or partner (53.5%). Most patients reported cohabitation of some type (77.1%), with 9.8% living with children, 7.3%

living with their parents, 4.6% living with a friend or companion, 0.8% living with a sibling, 0.8% living with a relative other than their parents, children, sibling, or spouse, and 0.3% living with a health related companion.

The participants in this sample are highly educated, with more than half having graduated college (60.2%). Nearly one-third have attended graduate school (24.5%). Only 15.3% of respondents reported having only attained a high school diploma, GED or attended a trade or vocational school (see Table 1).

Daily Activities

Analyses indicate the impact of CM on all types of daily activities varies significantly based on symptom severity (see Table 2). Those reporting minor symptoms found the greatest impact in housecleaning activities (2.4%) and computer usage (2.0%). Some respondents found shopping (1.2%) and driving (1.2%) to be impacted by CM symptoms. Patients with CM also reported walking up and down stairs (0.4%), doing laundry (0.4%), and holding a phone (0.4%) as being negatively impacted by their condition.

Daily activities were impacted more frequently for patients indicating moderate symptoms. Housecleaning (21.9%) was most commonly cited as being negatively impacted by CM symptoms. Participants reporting moderate symptom severity were 17 times more likely to report difficulty driving (20.6%) than those with mild symptoms. Going shopping (17.4%), walking up and down stairs (15.0%), and doing laundry (14.6%) were also negatively impacted. Participants with moderate symptoms also reported difficulty using a computer (13.8%), preparing food (9.7), and holding a phone (8.1%). Patients with moderate symptoms report issues with self-care, as 4.9% responded as having difficulty bathing or taking care of personal hygiene, getting dressed by themselves (4.0%), and difficulty going to the bathroom unassisted (0.8%).

Participants reporting severe CM symptoms were impacted across all areas of daily living and at much higher frequencies than minor or moderate symptoms. As with minor and moderate symptoms, housecleaning was the most often reported activity affected among those with severe CM symptoms (43.3%). Mobility was also frequently listed as being impacted, with 34.4% of patients indicating impact on their ability to drive, 33.2% reporting difficulty walking up and down stairs, and 33.6% having difficulty shopping for themselves. Household activities were also frequently impacted, with doing laundry (28.7%) and preparing food (27.1%) being most common. Use of communication technology was also frequently reported—21.5% of participants reported difficulty using a computer and 15.8% experienced trouble utilizing telephones.

Physical and recreational activities

In addition to ADLs and IADLs, CM impacted a wide range of physical and recreational activities (see Table 3). Nearly all (96.1%) of respondents reported at least one physical activity they can no longer engage in or enjoy due to CM symptoms.   Among those self-reporting minor symptoms 5.3% indicated walking and hiking, 2.8% bicycle riding, 2.8% running, and 2.0% yoga as activities they can no longer participate in or enjoy. Swimming (1.6%), dancing (1.6%), and spinning (1.2%) were also indicated as presenting difficulty for CM patients with minor symptoms.

Patients with CM indicating moderate symptom severity were more frequently impacted, typically exhibiting a two-fold increase in negative impact of physical activities compared to those suffering minor symptoms. Subjects indicating inability to engage in or enjoy walking or hiking increased to 18.6%. Likewise, 6.5% reported negative impact for running, 4.5% yoga, 5.3% weight training, 4.0% bike riding, and 4.0% swimming. Other areas subjects indicated inability to perform or enjoy included: dancing (3.2%), aerobics (2.4%), pilates (2.0%), and contact sports (2.8%).

Negative impact on physical activities results among subjects describing their CM symptoms as severe was uneven. Some physical activities were reported with greater frequency compared to moderate symptoms such as yoga (increased by 2.4% to 6.9%) and weight training (increased by 0.8%), others were less frequently indicated compared to moderate such as contact sports (decreased 0.8%) and running (decreased 1.6%). These decreases in contact sports and running among patients reporting severe symptoms may be a result of these patients never participating in these activities due to the typically chronic nature of many CM symptoms.

DISCUSSION

Similar to previous studies our sample population was predominately Caucasian females of Chiari Type I and age of symptom onset within the range of 19-45 years old[4]. Also consistent with prior research CM greatly impacts physical efficacy, translating to an inability to perform daily living activities[11]. The degree of self-reported symptom severity increases with greater extent of physical limitations. However, patients reporting mild CM symptoms are far less likely to experience negative daily living impact, although findings indicate one or more aspects of their physical or recreational life may have to be modified to adjust for the disorder. Furthermore, this assumption is consistent with the findings from this population—only 20% of this population are disabled due to CM, yet 96.1% report adverse impact on at least one aspect of daily living. This suggests that CM impacts nearly all patients' daily living activities to some degree.

Patients experiencing moderate or severe symptoms due to CM may have to radically alter their daily living activities. In many cases activities allowing for independent living, such as preparing food, getting dressed, or basic hygiene, may be compromised for severely symptomatic patients. The inability to care for oneself independently may help explain why less than 9% of the sample population lives alone and 23.6% lives with a family member other than a spouse. Adaptive services and long-term support provided to CM individuals would help to live a more independent life while being protected under the American with Disabilities Act Amendment Act of 2008.

In addition to compromising the independence of patients, CM also impacts mobility. The most commonly reported impact related to physical mobility was walking up and down stairs, running, and dancing. In addition to physical mobility, CM affects how participants can operate and utilize transportation. More than one-third of severely symptomatic and one-fifth of moderately affected patients with CM indicate difficulty or inability to drive an automobile. This can be especially problematic for patients with CM incapable of driving who reside in areas where public transportation is sporadic, inaccessible, or unavailable. Consequently, the decreased quality of life reported among patients with CM may be partially explained by the reduced independence experienced by these patients[14].Furthermore, patients lacking access to a family member, friend, or caregiver capable of providing transportation may find themselves isolated from work, medical care, shopping, and other critical aspects of daily living.

Related to the reduction of mobility is CM's impact on the ability to participate or perform recreational activities. As indicated earlier, CM restricts and limits many common recreational activities used for exercise. This finding suggests that patients with CM may be at risk for other health conditions resulting from lack of activity and exercise such as obesity, diabetes, and heart disease[15].

The data provided inconsistent results measuring foregone recreational activities among patients exhibiting severe symptoms. However, this may be explained as the question inquired about activities they can *no longer* do; patients experiencing severe CM symptoms over long periods of time are unlikely to engage in activities that caused them pain, discomfort or otherwise worsened their condition. In future research to assess impact on activities it would be advisable to ask subjects if they would be unable to participate in an activity due to their CM symptoms rather than if they were no longer able to engage in that activity.

Limitations

There are some limitations to this study including: (1) non-representational gender ratio, (2) disparities in online access to the survey, (3) partially complete surveys, (4) a preponderance of CM type I in the database and (5) controlling for related conditions. First, the gender ratio of the subjects is almost exclusively female (86.8%). Prior research[2,4] indicates that CM is more likely to affect women the disparity is less than observed in the current research. However, our sample approximates the same gender and demographic distributions observed in other large, CM studies[4]. As such, it is difficult to assess whether findings in this study apply to a more representative or generalizable population of CM patients. Second, use of the Internet as the sole manner of gathering data potentially excludes persons without online access. To remedy this shortcoming, the CCPR may seek to incorporate multiple formats in which to gather data. Third, due to the self-directed and open-ended format of the CCPR, in which patients choose which sections of questions to answer, many cases were incomplete and had to be omitted from analyses. Finally, the CCPR database consists of primarily CM type I diagnosis (81.8%). Due to the relatively few cases of non- Type I CM, results from this study may not be wholly representative of other CM types. Finally, it is unclear to what extent impact on ADLs and IADLs was a result of CM rather than related conditions. However, analyses were ran including only cases with no related conditions and the results were comparable. This indicates that it is the presence of CM that impacts the activities of patients with CM.

CONCLUSION

The impact CM has on daily activities can be debilitating. Almost all patients with CM experience lost capacity for daily activities even if presenting with minimal symptoms. Additionally, patient mobility—both physical and transportation utilization—can be compromised by CM, potentially leading to loss of the ability to live independently. As such, future research investigating the social vulnerabilities of patients with CM, ranging from social isolation, dependence on family member assistance and, inability to access medical services should be assessed. Furthermore, as CM manifests differently in each patient, there is need to correlate how specific CM symptoms impact different aspects of daily life.

REFERENCES

1. Mueller D, Oro JJ. Prospective analysis of self-perceived quality of life before and after posterior fossa decompression in 112 patients with Chiari malformation with or without syringomyelia. *Neurosurg Focus* 2005; 18(2): Ecp2.
2. Fernández AA, Guerrero AI, Martínez MI, et al. Malformations of the craniocervical junction (chiari type I and syringomyelia: classification, diagnosis and treatment). *BMC Musculoskeletal Disorders* 2009; 10 (Suppl 1).
3. Blount JP. Symptoms of the Chiari II malformation. In Tubbs, RS, and Oakes, WJ (eds) *The Chiari Malformations*. New York: Springer Science and Business Media. 2013:283-289.
4. Milhorat TH, Chou MW, Trinidad EM, et al. Chiari I malformation redefined: clinical and radiographic findings for 364 symptomatic patients. *Neurosurgery* 1999; 44(5): 1005-1017.
5. Ryan, R. E., & Pearlman, S. H. (2004). Common headache misdiagnoses. *Primary Care,31*, 395-405. doi:10.1016/j.pop.2004.02.010
6. Speer MC, Enterline DS, Mehltretter, L, et al. Chiari type I malformation with or without syringomyelia: prevalence and genetics. *Journal of Genetic Counseling* 2014; 12(4): 297-311.
7. Heiss JD, Oldfield EH. Treatment of the adult Chiari disorder. In Tubbs, RS, and Oakes, WJ (eds) *The Chiari Malformations*. New York: Springer Science and Business Media. 2013: 291-305.
8. Heiss JD. Epidemiology of the Chiari I malformation. In Tubbs, RS, and Oakes, WJ (eds) *The Chiari Malformations*. New York: Springer Science and Business Media. 2013: 83-92.

9. Zhang ZQ, Chen YQ, Chen YA, Wu X, Li, XG. Chiari I malformation associated with syringomyelia: a retrospective study of 316 surgically treated patients. *Spinal Cord* 2008; 46(5): 358-63.

10. Massimi L, Peppucci, E, Tamburrini G, Di Rocco, C. Sudden onset of Chiari malformation type I in previously asymptomatic patients. *Neurological Science* 2011; 32(S3): 263-265.

11. Sixt C, Riether F, Will BE, Tatagiba, MS, Roser, F. Evaluation of quality of life parameters in patients who have syringomyelia. *Journal of Clinical Neuroscience* 2009; 16(12): 1599-603.

12. Jenkinson, M. D., Campbell, S., Hayhurst, C., Clark, S., Kandasamy, J., Lee, M. K., . . . Mallucci, C. L. (2011). Cognitive and functional outcome in spina bifida–Chiari II malformation. *Childs Nervous System*, *27*, 967-974. doi:10.1007/s00381-010-1368-7

13. Labor Force Statistics from the Current Population Survey. Bureau of Labor Statistics web site, http://data.bls.gov/timeseries/LNS14000000. Accessed July 12, 2014.

14. Spector, W., Katz, S., Murphy, J., & Fulton, J. (1987). The hierarchical relationship between activities of daily living and instrumental activities of daily living1.*Journal of Chronic Diseases*, *40*(6), 481-489. doi:10.1016/0021-9681(87)90004-X

15. Booth F, Roberts C, Laye M. Lack of exercise is a major cause of chronic diseases. *Comprehensive Physiology* 2014; 2: 1143-1211.

The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

Table 1. Sample Demographics (n=798)

	n(%)
Respondent Age (mean, SD)*	40.8 (11.2)
Age at symptom onset (mean, SD)	20.5 (14.1)
Gender:	
Female	693 (86.8)
Male	64 (8.0)
Race:	
White or White-Hispanic	718 (90.0)
Black or African American or Black Hispanic	17 (2.1)
American Indian	31 (3.9)
Native Hawaiian	1 (0.1)
Other Pacific Islander	1 (0.1)
Asian	8 (1.0)
Prefer not to answer	4 (0.5)
Chiari Malformation Type:	
Type I	653 (81.8)
Type II	43 (5.4)
Other type	16 (2.0)
Employment Status:	
Disabled	163 (20.4)
Employed at home	25 (3.1)
Employed outside home	331 (41.5)
Homemaker	54 (6.8)
Retired	16 (2.0)
Student	65 (8.1)
Unemployed looking for work	26 (3.3)
Unemployed not looking for work	32 (4.0)
Worker's Compensation	6 (0.8)
Employment Status:	
Full-time	146 (18.3)
Part-time	51 (6.4)
Domestic Status:	
Living alone	66 (8.3)
Living with children	78 (9.8)
Living with friend/companion	37 (4.6)
Living with health related companion	2 (0.3)
Living with other relative	6 (0.8)
Living with parent	58 (7.3)
Living with sibling	6 (0.8)

Living with spouse/partner	427 (53.5)
Education:	
High School, GED, or vocational school	15 (15.3)
College	59 (60.2)
Graduate School	24 (24.5)

**Note: age calculation: (date of 6/24/2014 - date of birth)/365.25.*

The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

Table 2. Impact of Chiari Malformation on Daily Activities

Daily Activities	Severity of Symptoms		
	Minor (%)	Moderate (%)	Severe (%)
Bathing/personal hygiene	0.0	4.9	19.0
Getting dressed	0.0	4.0	17.0
Preparing food	0.0	9.7	27.1
Going to the bathroom unassisted	0.0	0.8	3.6
Walking up and down stairs	0.4	15.0	33.2
Doing laundry	0.4	14.6	28.7
Housecleaning	2.4	21.9	43.3
Holding a phone	0.4	8.1	15.8
Using a computer	2.0	13.8	21.5
Going shopping	1.2	17.4	33.6
Driving	1.2	20.6	34.4

The Impact of Chiari Malformation on Daily Activities: A Report from the National *Conquer Chiari Patient Registry* Database

Table 3. Impact of Chiari Malformation on Physical Activities

Recreational Activities	Severity of Symptoms		
	Minor (%)	Moderate (%)	Severe (%)
Walking/hiking	5.3	18.6	14.2
Swimming	1.6	4.0	6.1
Aerobics	1.2	2.4	2.4
Yoga	2.0	4.5	6.9
Contact sports	0.8	2.8	2.0
Dancing	1.6	3.2	3.2
Non-contact sports	0.8	2.4	1.6
Weight training	1.2	5.3	6.1
Pilates	0.4	2.0	1.6
Gymnastics	0.0	2.4	0.4
Running	2.8	6.5	4.9
Bike riding	2.8	4.0	4.0
Spinning	1.2	1.2	1.2
Other activities	0.8	3.2	2.4