In 1987, the National Institute on Disability and Rehabilitation Research (NIDRR) established the Traumatic Brain Injury Model Systems (TBIMS) to improve care and outcomes for people with traumatic brain injury (TBI). TBIMS Centers were created to focus on the full continuum of care provided to patients, from emergency services through lifelong follow-up. As the TBIMS program grew, research became an important facet of the program.

In 1998, Mayo Clinic successfully competed for the NIDRR grant that identified it as a Traumatic Brain Injury Model Systems Center, which has been continuously funded since then. Mayo’s center is one of the 16 currently funded TBI Model Systems Centers in the United States (Figure 1). Allen W. Brown, M.D., clinical director of Brain Rehabilitation at Mayo Clinic’s campus in Rochester, Minnesota, is the center’s principal investigator and project director.

Care provided
Mayo’s TBIMS Center provides comprehensive services along the continuum of care after traumatic brain injury. This includes acute care (emergency medical services, acute neurosurgical care, and so on), comprehensive inpatient rehabilitation services, and long-term interdisciplinary follow-up and rehabilitation services. Specialized staff also addresses patients’ social integration, health and function, and employment and independent living capabilities.

TBIMS data set
The TBIMS National Database is a longitudinal database that includes over 13,000 individuals who were admitted for inpatient acute TBI rehabilitation. In addition to pre-injury, injury, acute care and rehabilitation information, the database includes patient-reported outcomes at one, two and five years, and every five years thereafter for as long as they are living. Contributing to the largest nonproprietary longitudinal data sets in the world, all 16 centers add new subjects and submit follow-up data on a quarterly basis. Mayo Clinic collaborates with the other TBIMS Centers, using this data set to study outcome from all perspectives.

“Our research program is directly aligned with the NIDRR mission of improving the lives of individuals who experience TBI and their families,” explains Dr. Brown. “This work helps us gain a better understanding of the natural history of recovery following TBI and to identify factors that influence patient outcomes.”

Site-specific research
Mayo’s current TBIMS research project is a randomized clinical trial called CONNECT. This trial aims to connect target populations with specialized brain rehabilitation providers using traditional (telephone) and customized communication technology (Web-based,
smartphone, social media, Skype) to test the extent to which interventions delivered remotely improve participation outcomes and satisfaction, and provider capabilities, when compared with a matched group receiving usual care (Figure 2). Interventions include remotely connecting with individuals, their families and local providers to provide clinical expertise, coordinate care, and identify educational resources and community-based supportive services when needed or requested.

“CONNECT will test the interventions in four Midwest states — Minnesota, Iowa, North Dakota and South Dakota — with specific interest in rural dwellers and the elderly,” says Dr. Brown.

Module research
Mayo’s TBIMS Center is currently participating in three module research projects in collaboration with other TBIMS Centers:
- Internet use and online social media use among individuals with traumatic brain injury
- Testing the reliability of acquiring patient-reported TBIMS data by phone
- Resilience after traumatic brain injury

According to Dr. Brown, the Internet-use study will provide current data about how many patients with TBI access and use the Internet and other electronic media. This information will help providers determine whether online resources are a potentially effective way to provide care and resources for this patient population.

The second module study aims to validate the consistency of the data collected by TBIMS Centers. “We are essentially validating the bank of questions that TBI patients are asked during follow-up calls, so researchers can be confident that the data they collect is consistently accurate,” says Dr. Brown. And the third module study examines the data collected about patients’ outlook on life after TBI and how they handle challenges after returning to their families and communities.

“Ultimately our practice uses this research to inform clinical practice and improve patient care,” notes Dr. Brown. “We also want to be able to share these data with our national and international partners so we can better understand what’s happening globally to people living with TBI.”

For more information about the CONNECT trial:
http://www.mayo.edu/research/clinical-trials/cts-20089891
http://clinicaltrials.gov/show/NCT02088099

**Fibromyalgia Research Looks to Improve Treatment Strategies and Patient Outcomes**

Fibromyalgia is a condition characterized by widespread pain and a constellation of symptoms, including fatigue, poor sleep and cognitive symptoms. Affecting about 2 percent of the population and more common in women, this chronic disorder negatively affects quality of life.

Mayo Clinic’s comprehensive fibromyalgia treatment program was established in 1999 and is staffed by an interdisciplinary team that includes nurses, therapists, wellness coaches, nurse practitioners and physicians. Using data collected from more than 1,000 fibromyalgia patients who were treated at Mayo Clinic, Mayo researchers have performed a number of studies to learn more about this challenging condition and to improve treatment strategies and patient outcomes.

In 2010, Mayo Clinic physiatrist Terry H. Oh, M.D., and colleagues published long-term treatment outcomes for patients who completed Mayo Clinic’s 1.5-day fibromyalgia treatment program, which focuses on cognitive behavioral therapy. The majority of patients reported improvements in symptoms and quality of life (QOL) after completing the program, but some
did not improve, so Dr. Oh’s team became interested in identifying specific factors associated with treatment outcomes.

The predictors of clinical outcome study in fibromyalgia published in 2012 showed that those patients who reported greater benefit from the Mayo treatment program were younger and had more years of education, a higher baseline depression score on the fibromyalgia impact questionnaire (FIQ), a lower number of tender points, and no history of abuse.

Following the above studies, Mayo researchers began looking more closely at specific factors associated with symptoms and QOL in patients with fibromyalgia, including obesity, alcohol consumption and age.

**Body mass index**
Noting that obesity is more common in fibromyalgia patients than in the general population, Mayo researchers examined the relationship between body mass index (BMI), QOL and fibromyalgia symptoms. In a study published in 2012 in *Arthritis Care & Research*, Mayo researchers observed that about half of the 888 patients with fibromyalgia studied were obese, and of those, about 25 percent were severely obese (BMI ≥ 35). The Mayo research findings also showed that obese patients had worse fibromyalgia symptoms and QOL compared with nonobese and overweight patients. The differences in fibromyalgia symptoms and QOL were primarily noted among patients in the severely obese group.

According to Dr. Oh, this study highlights the importance of staying active and keeping weight off. “We recognize that it can be challenging for these patients to stay active when they experience chronic pain and fatigue, so it is important for us to understand the barriers to weight management that these patients encounter to be better able to help them.”

**Alcohol consumption**
Previous studies have shown positive relationships between alcohol consumption and conditions such as cardiovascular disease, chronic pain and rheumatoid arthritis. Building on that body of work, Mayo researchers decided to analyze the association between alcohol consumption, symptom severity and QOL among patients with fibromyalgia.

In a study published in *Arthritis Research & Therapy* in 2013, Mayo researchers analyzed self-reported alcohol consumption data obtained from 946 patients. Subjects were grouped by level of alcohol consumption (number of drinks consumed per week): none, low (≤ 3), moderate (> 3 to 7) and heavy (> 7). Five hundred and forty-six subjects (58 percent) reported that they did not consume alcohol, 338 (36 percent) reported low consumption, 31 (3 percent) reported moderate consumption, and 31 (3 percent) reported heavy levels of alcohol consumption.

This cross-sectional study demonstrates that low and moderate alcohol consumption were associated with less severe fibromyalgia symptoms and better QOL compared with no alcohol consumption. Drinkers had higher education, a lower BMI and a lower frequency of unemployment and opioid use than nondrinkers. Moderate alcohol consumption was associated with lower FIQ pain scores compared with low and heavy consumption, and moderate drinkers had a lower number of tender points than subjects in the low consumption group, even after adjusting for confounding covariates.

“These associations are intriguing,” says Dr. Oh, “but the reasons for these results are unclear. It would be premature to promote alcohol consumption as a means to relieve symptoms. We need to understand this association better.”

Interestingly, alcohol is known to be a gamma-aminobutyric acid (GABA) agonist, and recent studies have demonstrated that GABA levels are low in patients with fibromyalgia. But Dr. Oh cautions that more research is needed to more fully assess the relationship between fibromyalgia symptoms, GABA and alcohol use.

For comparisons of standardized PCS scores across the three age groups, the P value was < 0.001 between age ≤ 39 years and age ≥ 60 years, age 40 to 59 years and age ≥ 60 years, and age ≤ 39 years and age 40 to 59 years. For comparisons of standardized MCS scores across the three age groups, P = 0.006 between age 40 to 59 years and age ≥ 60 years, P < 0.001 between age ≤ 39 years and age 40 to 59 years, and P = 0.97 between age ≤ 39 years and age ≥ 60 years. The bottom and top of the box mark the 25th and 75th percentiles. The band inside the box marks the median, and the “x” marks the mean. The ends of the whiskers in this plot mark the minimum and maximum of the data. MCS = mental component summary; PCS = physical component summary. *Mayo Clinic Proceedings*. 2014:89:199. Used with permission.
Age
Dr. Oh notes that previously published studies have yielded conflicting findings when examining the relationship between age and symptom severity and QOL in fibromyalgia patients. In an article published in *Mayo Clinic Proceedings* in 2014, Mayo researchers studied 978 patients with fibromyalgia and divided them into three age groups: young (≤ 39 years), middle-aged (40-59 years) and older (≥ 60 years).

The Mayo study showed different symptom severity and QOL across the three age groups. The study findings showed that young and middle-aged patients had worse symptom burden and QOL than did older patients, while the differences between young and middle-aged patients were less pronounced.

When the standardized QOL of female fibromyalgia patients was compared with the QOL of the general female population of similar age, the fibromyalgia patients in all three age groups had lower QOL in physical as well as mental health. This difference was more prominent in the physical health, especially in young patients (Figure).

“This finding is particularly interesting, because in the general population physical health is negatively associated with age,” says Dr. Oh. “It is therefore important to address both mental and physical health, particularly in young patients, and incorporate exercise as an important component in treatment.”

In conclusion, Dr. Oh explains that the next phase of clinical investigations will examine whether modifying these factors and lifestyle variables, in combination with Mayo’s established treatment program, will improve symptoms, QOL and treatment response in patients with this challenging condition.

For more information


