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CONQUER CHIARI
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For Many Adults, Chiari Equals Pain

Chiari patients have long talked about having to deal with high levels of chronic pain, but a recent study from the Conquer Chiari Research Center (CCRC) quantified how bad the situation really is. The Physical Impact of Chiari Survey included a widely used pain scale called the Short Form McGill Pain Questionnaire 2 (SF-MPQ-2). The SF-MPQ-2 is comprised of 22 pain related terms such as throbbing, stabbing, shooting, aching, etc. Respondents are asked to rate their level of each type of pain experienced during the past week on a scale from 0 (no pain) to 10 (worst imaginable). More than 200 Chiari adults completed the survey, and the results were striking.

Specifically, 79% reported at least one of the 22 types of pain as a 7 or higher in the previous week. In addition, 28% of the Chiari patients rated 10 or more of the different types of pain as 7 or higher. Finally, 28% reported on or more pain types as being a 10 or the worst pain imaginable. Unfortunately, dealing with chronic pain at these high levels can have a profound effect on people across all aspects of their lives. Chronic pain has been linked to high blood pressure, poor mental health, increased healthcare costs, brain shrinkage, and even loss of religious faith.

So why do Chiari patients experience so much pain? Dr Philip Allen, Director of the CCRC, believes that for many Chiari individuals, central sensitization plays a large part. Central sensitization refers to structural and functional changes in the central nervous system (the brain and spine) which alter how pain signals are processed and perceived. The concept was developed in the late 1980's from rat studies that showed that after prolonged exposure to pain, their pain response systems became hypersensitized.

According to the Cleveland Clinic, in people this leads to three issues. First, normal pain signals are amplified (hyperalgesia). Second, stimulus which is not normally painful, such as a light touch, is perceived as painful (allodynia). Finally, global sensory hyperresponsiveness, in which people become more sensitive to a broad range of stimuli, such as loud noises, bright lights, strong smells, etc.

Central sensitization can be difficult to treat and often does not respond to pain medications. However, there is growing evidence that cognitive based approaches such as Acceptance and Commitment Therapy (ACT) can help people cope with the pain and engage in more activities. Because of this, Conquer Chiari has made a major commitment to investigating ACT therapy and plans on offering it to the Chiari community on wide scale basis in the near future.

Sources: Unpublished Conquer Chiari data; Cleveland Clinic Journal of Medicine (https://www.ccjm.org/content/90/4/245)

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