

Key Points

1. Very little - if any - research on how Chiari/syringomyelia affects marriage
2. However, significant research on similar diseases, such as MS and spinal cord injuries
3. This study followed 454 people with MS for 6 years to examine issues regarding marriage, acceptance of disability and perceived impairment
4. Research found that higher levels of marital concern were related to lower acceptance of disability, less health promoting activities, and higher perceived impairment
5. Men with MS were much more concerned about the sexual aspects of their marriage than women with MS
6. Study found that while both men and women grew more accepting of their disability over time, being consistently married had a significant positive effect for men, but not for women

Definitions

cerebellar tonsils - portion of the cerebellum located at the bottom, so named because of their shape

cerebellum - part of the brain located at the bottom of the skull, near the opening to the spinal area; important for muscle control, movement, and balance

cerebrospinal fluid (CSF) - clear liquid in the brain and spinal cord, acts as a shock absorber

Chiari malformation - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow

cross-sectional study - type of study which examines data collected from a single point of time; a snapshot of data

longitudinal study - type of study

Disease, Disability & Marriage

Given the relatively small amount of money devoted to Chiari and syringomyelia research over the years, it is not surprising that very little, if any, work has been done on studying the social impact of living with these conditions. With major medical questions involving the very definition of Chiari still unanswered, it is also unlikely that issues such as what impact living with Chiari has on a marriage are likely to be addressed anytime soon.

Fortunately, there are diseases which are similar to Chiari, such as Multiple Sclerosis (MS) and spinal cord injuries, which have received hundreds of millions of dollars of research funds over the years. MS affects about the same number of people as Chiari in the US (estimates range from 300,000 - 500,000), often strikes people in their 20's, 30's, and 40's, and even entails similar symptoms, such as eye problems, balance problems, and loss of feeling and strength in the arms and legs. Like Chiari, MS affects everyone differently; some people have mild symptoms that progress slowly, while others have severe symptoms which come and go over the years.

The similarities of MS and Chiari, combined with the relatively abundant amount of research on MS (and spinal cord injuries) presents us with a method of assessing some of the social issues of living with Chiari indirectly, and for the time being, bypassing the lack of funding on Chiari research.

For example, research on MS, spinal cord injuries, and other diseases, has shown that people who can accept their disease and any accompanying disabilities tend to be in better health, take better care of themselves, and have a higher quality of life. Research has also shown that this acceptance is influenced by a person's social environment, and in particular their marriage. Interactions with their spouse, and the perceptions of their spouse on the situation, play a role in how well people with a chronic disease perceive themselves.

Along these lines, research has also shown that marriage is associated with better health for people with disabilities. This includes less depression, higher life satisfaction, and a higher quality of life. Of course, the intrusion of a disease and disability into a marriage can be difficult to handle, especially if one partner has to provide care for the other. This can be particularly troublesome if it results in activities that go against traditional gender roles. Specifically, men may have problems with care giving tasks, and women may feel guilty about their need for help. In fact, studies have shown that women who develop disabilities during a marriage often report that their marriage has suffered because of their inability to perform household tasks and engage in activities with their husbands.

While the research cited above gives an interesting view into some of the issues associated with disease and marriage, much of this type of research is based on cross-sectional studies, meaning that the data was gathered at one point in time. Cross-sectional studies are good at providing snapshots of a situation, but as anyone who is married knows, marriage is generally a long-term endeavor filled with many ups and downs.

With this in mind, Tracie Harrison, from the School of Nursing at the University of Texas at Austin, and several nursing colleagues, decided to study the relationship between marital status, gender, and health related outcomes of people with MS over a 6 year period. (see Figure 1)

Figure 1
Study Definitions

acceptance of disability - when someone accepts a disability, they come to believe that it is part of who they are, and not in a negative way

marital concern - perception that there are problems in a marriage due to sexual concerns, performance of tasks, emotional tension, or worry about a partner

health promoting behaviors - activities which are done to improve one's health and well-being

perceived impairment - subjective sense of limitations on physical activities, or the need for assistance

They recruited 454 people from an ongoing, long-term study, and gathered information - via surveys - on a yearly basis regarding demographics, acceptance of their disability, perceived impairment, health promoting behaviors, and the level of marital concern (see Figure 2). They reported their results in the April, 2004 issue of the Western Journal of Nursing Research.

Demographically, the study participants were predominantly women (377, compared to 77 men), mostly white Anglo-Saxon, and about half were college educated. The average age of the men was 50 years and the women 47 years. At the time the study started, 73% of the men were married and 75% of the women. Over the course

in which participants are followed, and data is collected, over a long period of time

multiple sclerosis (MS) -

neurological disease which, for unknown reasons, gradually destroys the coverings - myelin - of nerves

syringomyelia (SM) -

neurological condition where a fluid filled cyst forms in the spinal cord

syrinx - fluid filled cyst in the spinal cord

Source

Harrison T, Stuijbergen A, Adachi E, Becker H. Marriage, impairment, and acceptance in persons with multiple sclerosis. *West J Nurs Res.* 2004 Apr;26(3):266-85

of the 6 year study however, only 66% of the women were consistently married, whereas 72% of the men remained married.

Figure 2 **Overview of Surveys Tools Used**

Demographics - Background information was collected on age, gender, ethnicity, employment status, education, and marital status

Acceptance of Disability - The Acceptance of Illness scale was used; 14 questions such as, "having a disease like MS is just part of life", answered on a 1 (strongly agree) to 5 (strongly disagree) scale

Perceived Impairment - Incapacity Status Scale was used; 16 items answered on a scale of 0 (normal functioning) to 4 (complete inability); example item, "Are you able to walk up and down a flight of 12 steps?"

Health Promoting Behaviors - Health Promoting Lifestyle Profile II was used; 52 questions to assess how frequently a person does activities that enhance physical or mental health; each behavior is rated on a scale from 1 (never done) to 4 (routinely done).

Marital Concern - A scale was created by taking 14 items from the Demands of Illness Inventory Scale, to assess the impact of MS on marriage

As the researchers suspected, there was a strong relationship between increased levels of marital concern and lower levels of disability acceptance and higher perceived levels of impairment. In other words, people who reported they were not as accepting of their condition, and/or felt more limited in their activities, tended to be more worried about their marriage and thought there was conflict in their marriage. This relationship extended to overall health as well, with people who scored lower on health promoting behaviors also reporting more marital concern.

The marital concern responses (of those who were married at the time of the study) were further analyzed to identify any gender based differences among the subjects. Using statistics, the researchers identified four factors of the marital concern survey: sexuality, perceived marital strain, concern for the amount of tasks their partner has to perform, and overall concern for their partner. Interestingly, there were no statistical differences between the men and women on the responses regarding marital strain, tasks, and partner concern. However, for the sexuality component, men reported much higher levels of concern than women did.

In analyzing the longitudinal nature of their study, the researchers found that both men's and women's acceptance of their disability increased over time. This was true despite a corresponding increase in perceived impairment. This finding may be related to the absolute age of the participants as the study went on. Spinal cord injury research has shown that the younger someone is at the time of their injury, the more difficulty they have accepting their situation.

Perhaps the most interesting result of the study was that although both men and women grew more accepting of their disability as time went on, this was especially true for men who stayed married. Men who were married throughout the study consistently reported higher levels of disability acceptance and lower levels of perceived impairment than their unmarried, divorced, or widowed counterparts. However, this was not true for the women. Among the women, there was no relationship between marital status and the levels of disability acceptance and perceived impairment.

The researchers speculate that for men, their spouse tends to provide the majority of social support; whereas women tend to have more sophisticated social networks and are able to compensate for the absence of a spouse. *[Ed. Note: At the risk of adding some levity to a serious subject, this finding would appear to support the saying popularized in the '70's, "A woman needs a man like a fish needs a bicycle."]*

While the longitudinal nature of this study provides some strong results, the authors acknowledge the study is somewhat limited because all of the data is self-reported and only takes into account the perceptions of one of the marriage partners. Despite this, the results are interesting, and if nothing else highlight the complex nature of how something like Chiari may impact a marriage, and point to the need for a great deal more research.

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