Syringomyelia | 01.04

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Key Points

1. Qualitative, phenomenological study looked at one man's experiences living with syringomyelia
2. Researchers employed open ended questions over a period of several months to collect data
3. Responses were interpreted and formed into themes
4. Overarching theme was one of "Engulfment By The Disease"
5. 3 themes and 11 sub-themes were identified (see below)
6. Because of the case-study nature of the research, scientifically, the results can not be generalized to other people

Definitions

case study - type of research which focuses on one subject, or person, as opposed to a group of subjects

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

cervical - relating to the upper portion of the spinal cord, the neck area

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

decompression surgery - common term for any of several variations of a surgical procedure to alleviate a Chiari malformation

Dr. Max van Manen - scientist who developed a phenomenological research method which is widely used

hermeneutic - interpreted

One Man's Experience With Syringomyelia

Most of the research discussed in this publication is what is known as quantitative research. In quantitative research, the data collected is in numerical form and statistics are used to analyze the results and draw conclusions. For example, a question is posed (does the amount of bone removed during decompression surgery affect how quickly patient's recover and how much pain they experience), a group of subjects is identified (Chiari patients), variables to be examined are identified and quantified (amount of bone removed in square inches, self-reported pain on a scale from 0-100, number of days to resume daily activities), and the data is collected. Statistical techniques are then used to analyze the results and determine if indeed the amount of bone removed affects how much pain patients experience and how quickly they recover. Quantitative research is very useful in answering specific questions, and is the backbone of true medical progress, but because numbers are used to represent people, feelings, and events, the results can also be - from a patient's point of view - somewhat superficial.

What was it like for the subjects to go back to work? Was it extremely difficult for some, but easier for others? Did some people feel pressure to resume their activities more quickly? Was it a strange feeling to have a large piece of bone removed versus a small one? Were some people more worried about further injury because of the amount of bone removed?

These types of questions can be difficult to examine using quantitative methods. In response to these limitations, a second type of research has evolved over the years, qualitative research. In qualitative research, the data collected is in the form of words and descriptions. Participants are often encouraged to discuss things at length through the use of open-ended questions (how do you feel about this?) or observers write down descriptions of what they see. While it is difficult for qualitative research to definitively answer specific questions, it often provides a level of humanistic insight that is missing with quantitative research.

One specific type of qualitative research is known as phenomenological research. This type of research - which has philosophical underpinnings - emphasizes a person's experiences and often looks in-depth at what a certain type of person's life is like across many dimensions. These types of studies use the term "lived experiences" and gain insight into people through the use of interviews, surveys, and open-ended questions. The descriptive results aren't so much analyzed as they are interpreted in an attempt to draw meaning from the responses.

Edith Hilton, RN, Ph.D., a nursing professor at North Park University, in Chicago, and her colleague, Lesley Henderson, RN, MSN, at the State University of West Georgia, performed just such a study on a man living with Chiari and syringomyelia. They published their results in the Spring 2003 issue of the journal SCI Nursing. The researchers employed a technique known as the Van Manen Method of Hermeneutic Phenomenology to study a middle-aged white man living in the Midwest - who they called "Greg" - with a long history of Chiari and syringomyelia. Data was collected in the form of responses to open-ended questions over a several month period in the man's home. The questions were designed to stimulate the man's memories and elicit experiential responses.

The responses were professionally transcribed and analyzed in an attempt to identify common themes (see Side Bar). The team identified one over-arching theme, three main themes and eleven sub-themes. The over-arching theme was one of total engulfment by the disease. Greg revealed that the disease, and the accompanying feelings of endless striving, sorrow, disappointment and melancholy, had seeped into every aspect of his life and had fundamentally changed his personality.

Not unexpectedly, Loss of Abilities was one of the main themes the researchers uncovered. They further broke this down into the sub-themes Health and Wellness, Unexpected Changes, and Living With Loss. The loss of abilities is something many people with syringomyelia have to deal with and many, like Greg, retreat into their homes, "Around that time I became a social isolate. I was tired when I got home, and Brenda [his wife] was tired from taking care of the girls all day. We basically just stopped going out," he said. As Greg's symptoms became worse, travel became more and more difficult and eventually walking became difficult. Despite these losses, like many people, Greg went to great lengths to hide his problems - especially at work - and not complain about them.

Struggling To Adapt To Changes was the second theme identified by the researchers. Greg struggled through misdiagnoses, frustrations in dealing with doctors, and the reality that despite surgery his symptoms were not going to improve much. One of the hardest places to adapt to physical changes is at work, and Greg described his struggle to hide his disability from his coworkers. Afraid of how they would treat him, he became alienated from his fellow employees and as the pain built, it finally became too much. He left work suddenly and decided to go on disability.

The third main theme in Greg's experience base was identified as Life As A Man With A Disability. Struggling to accept his disability, Greg expressed frustration about his lack of autonomy and how his relationship with his

phenomenological - relating to experiences; phenomenological research emphasizes the importance of how people experience and feel things

qualitative research - type of research which uses words and descriptions as data

quantitative research - type of research which uses numbers for data and statistics to analyze results

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

syrinx - fluid filled cyst in the spinal cord

Source

Hilton EL, Henderson LJ; The Nature, Meanings, and Dynamics of Lived Experiences of a Person With Syringomyelia: A Phenomenological Study. SCI Nursing Spring 2003, 20(1): 10-17

wife had changed. Greg also was frustrated with the lack of awareness of his condition among the general public, "If I had fallen and become a quadriplegic breathing through a hole in my neck, at least people would understand my problem...I've lost a lot, but it's hard for people to see what I've lost because I'm still standing...It's all invisible."

Despite the overwhelming - and generally negative - nature of Greg's experiences, he was able to focus on some positives, "After my symptoms got to where I couldn't do my job, I had to stay home and my wife went out to work. Everyday, when my wife walked in the door, the house was clean, supper was on the table, and the girls and I would work on their homework together...my girls had more time with their father than many kids have so it was good in that respect." Greg found his daughters to be very kind, understanding, and supportive. To them, he had always had this condition, so the ups and downs that went with it was just the way it was.

It should be noted that the researchers did try to help Greg during the course of their study. They worked with Greg to solve practical problems that arose because of his symptoms and identified community resources that could help him. They played the role of an active listener and expressed an interest and engagement in his life and experiences. Finally, they helped Greg work through life plans and identify new priorities - such as maintaining a healthy lifestyle - given the reality of his situation.

It should also be pointed out that while many may see echoes of their own experiences and problems in Greg's descriptions, scientifically, the results of this study are not applicable outside of this one case. Anecdotally, there are a wide range of experiences with Chiari and syringomyelia. To generalize these results, the same study would have to be performed on many more people and the same - or similar - themes identified.

Despite this limitation, it is interesting to get a glimpse into one man's struggles with this disease and for the medical community to take a different approach to studying it.

Identified Themes - Engulfment By The Disease

1. Loss of Abilities	2. Struggles To Adapt	3. Life As A Man With A Disability
Health and Wellness	Anger & Frustration	Losses In Family Life
Unexpected Changes	Hiding the Symptoms	Finding Humor In Sadness
Living With Loss	Escaping With Sleep	Moving Forward
	Discovering Disability	