Patients Define Success

November 15, 2005 -- When it comes to treating medical problems, defining success is not always easy. For some types of cancer, success might be becoming cancer free; for a life-threatening disease, success might be an improved survival rate. As this publication has pointed out previously, success in treating Chiari is often defined based on MRI's and does not take into account patient focused issues such as ability to work and engage in recreational and social activities.

While we still have a long way to go in redefining Chiari success, Dr. Michael Robinson, of the University of Florida's Clinical and Health Psychology Department, along with a multi-disciplinary group of colleagues, recently looked at how patients, not doctors or researchers, define success in terms of treating chronic pain.

Pain research often uses simple number scales to assess pain levels before and after a treatment. Researchers then use statistics to see if there was a significant improvement for a given treatment. In this case, significant is a statistical term which means that the improvement was not likely to be due to chance. However, defining success in this way has several drawbacks.

First, statistical significance is strongly influenced by the number of data points being analyzed. In other words, in a study which uses a large number of subjects, a small change in scores might be statistically significant. The problem is that the improvement might be so small as to not really represent a noticeable change for the patients. Researchers refer to this as a result not being clinically significant.

A second difficulty in measuring pain treatment success is that pain is complicated, multi-dimensional, subjective, and influenced by things such as mood and ability to cope. These factors call into question the validity of a simple "is your pain better" approach to defining success. For example, one study found that while patients obviously wanted pain relief from their treatment, they also wanted to be able to sleep better and engage in their daily activities.

Finally, because pain is so subjective, rating the success of a treatment can be influenced by expectations. Think about going to see a movie; if the movie has been hyped as the best movie of the year, it is easy to be disappointed once you see it. Conversely, if you aren't expecting much out of a movie, it is easy to be surprised and enjoy it more than expected. Expectations can play a similar role in treating pain and have been shown to influence how treatments are rated.

In an effort to take these factors into account, the University of Florida team designed a survey (see Figure 1) which asked 110 chronic pain patients to rate their usual levels of pain, fatigue, emotional distress, and how much pain interfered with their daily activities, all on a scale of 0 (none) to 10 (worst imaginable). The pain patients then performed a similar rating - for the four categories - to say what they would consider an appropriate level after a successful treatment. A third question asked, again for the four categories, what the patients expected after their treatment. Finally, the group was asked to rate how important improvement in each category was.

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Figure 1

Selected Questions From PCOQ Questionnaire

First, we would like to know your usual levels of pain, fatigue, emotional distress, and interference.

On a scale of 0 (none) to 10 (worst imaginable), please indicate your usual level (during the past week) of...

- pain
- fatigue
- emotional distress
- interference with daily activities

Similar questions were then included for:

- desired levels of pain, fatigue, etc.
- patient defined success after treatment for each area
- expected levels after treatment for each area
- importance of having improvement in each area

The patient group was comprised of 60 women and 50 men recruited from four pain clinics. The majority were suffering from back pain, but some were there for neck pain, facial pain, arthritis, fibromyalgia, and headaches. On average, they had been suffering for more than 7 years, and likely as a result, only about 1/4 were fully employed.

Interestingly, the scientists found that patients defined success a little differently than most pain researchers had in the past. They published their results in the September, 2005 issue of Pain Medicine. Specifically (see Table 1, Table 2) the group rated their usual levels of pain, fatigue, distress, and interference in the moderate range (5-6), but defined success as substantial improvements across the board, 56%-68%. Interestingly, success for pain required the least improvement, whereas success for interference with daily activities required the most. The authors point out that this level of improvement is higher than the 30% number which some researchers use in studying pain. The authors also point out that while the patients defined success as substantial improvements, they did not define success as complete recovery (meaning a score of 0 in each category), likely reflecting a realistic assessment of their situation.

Looking at what the patients expected the outcomes of their treatments to be revealed that in general they expected a successful treatment (as measure by their definition) in terms of pain and fatigue; however, for reasons that are not clear, they did not expect the treatment to be successful in terms of interference with daily activities.

Finally, when analyzing how patients rated the importance of improving in each area, the researchers identified three distinct groups, or clusters. One group rated improvement in each of the four areas as extremely important (close to 10 in each category). A second group rated improvement in each group as moderately important, and the third group rated only improvement in the pain category as important. The authors believe the clustering patients into categories underscores that not all pain patients are the same and that they need to be evaluated and treated on a case by case basis.

While there are certainly some limitations to this research, it is encouraging to see researchers recognize in at least one area that defining success should take into account the patient’s perspective and expectations. Hopefully Chiari researchers will take note and do the same.

<table>
<thead>
<tr>
<th></th>
<th>Pain</th>
<th>Fatigue</th>
<th>Distress</th>
<th>Interf</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usual</td>
<td>6.1</td>
<td>5.9</td>
<td>5.5</td>
<td>6.4</td>
</tr>
<tr>
<td>Success</td>
<td>2.7</td>
<td>2.6</td>
<td>1.8</td>
<td>2.0</td>
</tr>
<tr>
<td>Expected</td>
<td>2.7</td>
<td>2.5</td>
<td>2.2</td>
<td>2.6</td>
</tr>
<tr>
<td>Importance</td>
<td>9.2</td>
<td>8.4</td>
<td>7.7</td>
<td>8.2</td>
</tr>
</tbody>
</table>

Note: Distress refers to Emotional Distress, Interf refers to Interference with Daily Activities
### Table 2
Patient Defined Success

<table>
<thead>
<tr>
<th>Category</th>
<th>% Improvement Defined As Success</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>56%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>57%</td>
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<tr>
<td>Distress</td>
<td>65%</td>
</tr>
<tr>
<td>Interference</td>
<td>68%</td>
</tr>
</tbody>
</table>

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