Key Points

1. Chronic pain has clearly been linked to anxiety, depression, and poor psychological adjustment.
2. Study examined the effects of talking about chronic pain.
3. 190 pain patients answered a series of questionnaires to assess who they talk to about their pain, how often they talk about it, and their satisfaction with talking about it.
4. Study found that people talked most frequently with their spouses, family doctors, and pain clinic doctors.
5. However, people found talking with other ill people the most satisfying, followed by talking with a psychologist.
6. Study found that if people felt constrained in talking about their pain, or if they thought they weren't believed, there was a negative impact on their psychological adjustment.
7. Study also found that people who had symptoms for more than a year before being diagnosed were negatively impacted psychologically and socially.

Figure 1

Verbalization of Chronic Pain -

As a tool to identify who they talk to about their pain in the past 30 days; the content of the conversation (factual, emotional); and their satisfaction (on a scale of 1-5) with the sharing.

Social Constraint - Lepore, Silver, Wortman, Wayment

A questionnaire adjusted to chronic pain; 5 questions such as, "Do you keep your feelings about your illness to yourself because they make other people uncomfortable?"; each question rated on a 5 point scale 1=almost never, 5=almost always.

Perceived Credibility - 5

Questions answered on a 5 point scale 1=never, 5=almost always.

Talking About Chronic Pain

It is well established that living with chronic pain can have a large, negative impact on a person's quality of life.

Chronic pain is associated with anxiety, depression, and a lower level of life satisfaction. Judging from the emails this publication receives, one factor contributing to this negative outcome is the feeling of chronic pain patients that people don't understand what they are going through and expect them to just shrug off the pain.

In fact, research has shown that many "victims of life events", such as disaster survivors or chronic illness sufferers, report that the way people treat them actually discourages them or limits their emotional expression.

This type of behavior by others, such as minimizing the situation, giving unwanted advice, making insensitive remarks, etc., is referred to as social constraint by psychologists.

Social constraint is not just a patient perceived phenomenon either. Studies have shown that families of seriously ill people often avoid serious health conversations and that healthy people feel that someone shouldn't talk about their illness or pain. Often, instead of listening, people feel like they need to cheer someone up who is talking about being sick or in pain.

A second factor which might contribute to a chronic pain patient's anxiety and depression is the feeling that people don't believe they are actually in pain. This lack of credibility, of pain or a disease which can't be seen, can lead to self-doubt and feelings of shame in a person. Unfortunately, all too often, this perceived lack of credibility is actually a reality.

Research has shown that people respond differently to patients with illnesses that are attributable to legitimate causes, as opposed to those whose cause of illness is not readily apparent. In one study, hospital nurses were given a description of two hypothetical patients. Patient one had suffered from pain for a long time with an inconclusive diagnosis and showed signs of depression. Patient two suffered from pain for a short time from a well-defined cause and showed no signs of depression. Surprisingly, the nurses believed the chronic pain patient was suffering much less than the acute pain patient. The absence of a definitive diagnosis was often interpreted as meaning nothing was really wrong with the chronic pain patient.

Against this backdrop of what chronic pain patients face, two psychologists from Belgium, Dr. Herbette and Dr. Rime, wanted to study how people talk about their chronic pain, and how talking about it affects their psychological adjustment.

They recruited 190 patients from two pain clinics and collected data (see Figure 1) on who they talk to about their pain, what they talk about, how satisfied they are with their health conversations, whether they feel socially constrained in talking about their pain, whether their condition appeared to be credible, and their psychological adjustment. They published their results in the September, 2004 issue of the Journal of Health Psychology.

The group of respondents was predominantly female (78%) and on average was 48 years old. 68% were married and 40% employed. The group was fairly well educated with more than half having completed at least 12 years of school. The most common source of pain was fibromyalgia, which affected about 44% of the group, but there were many other causes as well, such as slipped discs, neuropathic pain, breast cancer, osteoarthritis, and others.

In looking at who people talk with about their pain, not surprisingly, spouses were the most frequent verbalization partner (see Table 2). This was followed by the family doctor and pain specialists. Interestingly, parents, siblings, and children were used less frequently than not only doctors, but close friends as well.

While spouses were the most frequent conversation partners, they were rated fairly low by the patients in terms of satisfaction of the discussions (3.5 out of 5). Speaking with other ill people was rated as the most satisfying (4.31 out of 5), followed closely by speaking with a psychologist (4.26 out of 5). In fact, spouses rated lower than doctors, close friends, and even physical therapists.

However, when the group was asked who they got the most benefit from talking with, spouses again ranked at the top. The researchers try to explain this discrepancy between satisfaction and benefits by speculating that the availability of spouses to communicate with makes up for the lack of satisfaction with each individual conversation.

In looking at overall psychological adjustment, the researchers found, not surprisingly, that social constraint and perceived credibility had an impact on psychological well-being. Social constraint (feeling like they couldn't talk about their pain) had a negative impact on people's psychological adjustment, and perceived credibility had a positive impact. In other words, patients felt better psychologically if they thought other people believed they were really in pain. Simply validating that there is something wrong can have a positive effect on a person.
scale 1=not at all, 5=to a great extent, assessing whether their problem had been clearly identified by a doctor, to what extent they understood the origins of their pain themselves, and to what extent it was understood by those around them.

Psychological Adjustment - Pain Anxiety Symptoms Scale; 40 questions answered on a 5 point scale 1=never, 5=always; questions such as, "I feel that if the pain becomes too strong, it will never decrease."

Also completed Hospital Anxiety and Depression Scale; 7 questions assessing anxiety, 7 questions assessing depression.

Also completed Rosenberg’s self-esteem questionnaire; 10 questions answered on a 5 point scale 1=completely disagree, 5=completely agree; questions such as, "I feel I am a person of worth, at least on an equal plane with others."

Finally, the researchers found that while total duration of symptoms didn’t have much effect on how people talked about their pain, the time between onset of symptoms and diagnosis had an impact on a number of variables. People who had symptoms for more than a year before being accurately diagnosed showed poorer psychological adjustment, were more socially constrained, reported a lower credibility level for their illness, and even reported a lower level of physical well-being. It appears that the time between onset of symptoms and diagnosis can play a big role not only in how others respond to a person’s illness, but also in how people feel about their own situation.

While the entire study provides an interesting look into how people verbalize chronic pain, this last finding is particularly troublesome for Chiari and syringomyelia patients who often go years - and through many doctors - before being properly diagnosed.

Table 2
Selected Results Of Chronic Pain Verbalization Questionnaire

<table>
<thead>
<tr>
<th>Person Spoken To</th>
<th>Frequency (% Of All Partners)</th>
<th>Satisfaction With Sharing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>16.88</td>
<td>3.52</td>
</tr>
<tr>
<td>Family Doctor</td>
<td>12.40</td>
<td>3.67</td>
</tr>
<tr>
<td>Pain Doctor</td>
<td>10.10</td>
<td>3.99</td>
</tr>
<tr>
<td>Close Friends</td>
<td>9.85</td>
<td>3.83</td>
</tr>
<tr>
<td>Psychologist</td>
<td>3.96</td>
<td>4.26</td>
</tr>
<tr>
<td>Other Ill Person</td>
<td>1.66</td>
<td>4.31</td>
</tr>
</tbody>
</table>

Note: Frequency refers to the percentage of all partners who are in this category; Satisfaction was rated on a scale of 1-5, with 5 being very satisfied.

Source