Diseases of the nervous system: patients’ aetiological beliefs

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Background: Patients’ opinions about the aetiology of their disease and the implications for compliance have not been well documented at this time.

Objective: To investigate prospectively aetiological beliefs of a cohort of neurological inpatients.

Methods: Within two days of admission, patients orally answered a short questionnaire regarding their beliefs about the aetiology of their disease and the possible influence of psychological factors, stress, fatigue, excessive work or other activities, poor lifestyle, conflict with another person, a tragic event, chance, and destiny.

Results: Of the 342 patients who participated in the study, 49% spontaneously said that they had no idea of what could have caused their disease, 15% gave a congruent medical explanation, 11% mentioned stress and fatigue as a precipitating factor, and 6% evoked a non-congruent medical explanation. Thirty-six per cent thought that psychological factors had triggered their disease; such factors being blamed by a higher proportion of young patients and patients with chronic central nervous system diseases. The triggering factors most often blamed were stress (48%, especially by patients with headache), fatigue (51%), chance (54%), and destiny (43%).

Conclusions: Patients’ aetiological beliefs only partially correspond with medical opinion and this may influence compliance with treatment. This statement should be explored and confirmed by further studies—for example, in cerebrovascular risk factor follow up.

Patients are often unaware of, or do not understand about, recent developments in molecular and genetic medicine and more technical interventional therapies. Thus when patients search for explanations for triggers and the evolution of their disorder they often blame, for instance, psychological factors or special events.

We hypothesised that this could result in divergence of opinion between the patient and the doctor, which, in turn, might lead to poor compliance with the proposed treatment. A British study of patients in general practice showed that only half the patients thought they would benefit from medical treatment or hospitalisation for investigations. The failure of conventional medicine to take into account psychological aspects of illness may be one reason for the recent enthusiasm for alternative and complementary therapies. Another reason for evaluating patients’ beliefs about psychological factors is that these factors have been described as a possible influence on the triggering of diseases.

In addition, there is recent evidence for a beneficial effect of spiritual belief on the evolution of chronic disorders and on patients’ ability to cope with the disease. Stress and excessive workload have also been recently recognised as possible factors in the development of chronic pain syndrome, with or without anatomical lesions.

To evaluate these aspects of clinical practice, we asked patients to reply orally to a short questionnaire during the first two days after admission to a neurology inpatient department.

Materials and methods

Of 750 consecutive inpatients admitted to our neurology department between November 2001 and June 2002, 41 patients refused to answer the short questionnaire and 367 were unable to answer within two days of admission (critically ill, demented, confused, severely aphasias, and anosognosic patients). The remaining 342 patients (49% women, 51% men; mean (SD) age 61 (19) years) participated in the study. These patients answered a short questionnaire consisting of three questions:

1) The first question was open ended to evaluate spontaneous answers: “What do you think triggered your disease?”

2) The second question assessed psychological factors in general: “Do you think that psychological factors played a role in triggering it?”

3) The third question explored whether the following factors could have triggered the patient’s disease: stress, fatigue, excessive work or other activities, poor lifestyle, conflict with another person, tragic event, chance, and destiny.

The diagnosis was made on the basis of a standard, generally accepted work up and patients were classified as having stroke (n = 177), chronic central nervous system (CNS) disease (n = 41; mainly parkinsonism and inflammatory diseases), epilepsy (n = 27), headaches (n = 16), peripheral nervous system (PNS) disease (n = 30), or non-classified diseases (n = 51).

Results

When answering the first open ended question, 49% of patients included in the study spontaneously admitted that they had no idea of what could have caused their disease (95% confidence limit (CL) 43.7% to 54.3%), 15% gave a congruent medical explanation (95% CL 11.2% to 18.8%), 11% mentioned stress and fatigue as a precipitating factor (95% CL 7.7% to 14.3%), 6% mentioned a psychological event or a dysphoria (95% CL 3.5% to 8.5%), and 6% gave a non-congruent medical explanation (95% CL 3.5% to 8.5%). Some answers could not be classified into any of the aforementioned categories: one patient said that he was convinced that a portable phone antenna placed next to his house was responsible for triggering his transient aphasia symptoms, and another patient, who had had a right middle cerebral

Abbreviations: CL, confidence limit; CNS, central nervous system; PNS, peripheral nervous system
Factors blamed by the different groups (%)

<table>
<thead>
<tr>
<th>Factors</th>
<th>Strokes (n = 177)</th>
<th>Chronic CNS diseases (n = 41)</th>
<th>Epilepsy (n = 27)</th>
<th>Headaches (n = 16)</th>
<th>PNS diseases (n = 30)</th>
<th>( \chi^2 ) test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>45</td>
<td>48</td>
<td>55</td>
<td>81</td>
<td>33</td>
<td>p = 0.029</td>
</tr>
<tr>
<td>Fatigue</td>
<td>46</td>
<td>65</td>
<td>44</td>
<td>43</td>
<td>56</td>
<td>p = 0.205</td>
</tr>
<tr>
<td>Excessive work or other activities</td>
<td>27</td>
<td>34</td>
<td>14</td>
<td>43</td>
<td>33</td>
<td>p = 0.234</td>
</tr>
<tr>
<td>Poor lifestyle</td>
<td>16</td>
<td>21</td>
<td>14</td>
<td>12</td>
<td>6</td>
<td>p = 0.518</td>
</tr>
<tr>
<td>Conflict with another person</td>
<td>9</td>
<td>17</td>
<td>18</td>
<td>31</td>
<td>16</td>
<td>p = 0.093</td>
</tr>
<tr>
<td>Tragic event</td>
<td>16</td>
<td>21</td>
<td>22</td>
<td>43</td>
<td>13</td>
<td>p = 0.084</td>
</tr>
<tr>
<td>Chance</td>
<td>53</td>
<td>63</td>
<td>44</td>
<td>43</td>
<td>46</td>
<td>p = 0.451</td>
</tr>
<tr>
<td>Destiny</td>
<td>44</td>
<td>46</td>
<td>51</td>
<td>25</td>
<td>20</td>
<td>p = 0.043</td>
</tr>
</tbody>
</table>

DISCUSSION

As the understanding of disease mechanisms and the diagnostic tools used become more complex and specialised, patients’ beliefs may only partially comprehend their disease. Some beliefs of patients may overlap those of their doctors and some may not, and this could influence their compliance with therapy. In our study, only 15% of patients gave a congruent medical explanation when asked about what could have caused their disease and more than a third believed that psychological factors had played a role in triggering it. Only 16% of stroke patients mentioned a poor lifestyle, whereas many studies have described environmental and lifestyle factors as important in causing cerebrovascular diseases.

In contrast, chance and destiny were frequently mentioned by the patients, which, at least for cerebrovascular disease, does not agree with the medical opinion that genetic, environmental, and lifestyle factors are responsible for the development of the majority of cerebrovascular events.

On the other hand, some studies have described psychological factors in triggering various diseases such as...
coronary heart disease,14 fatigue and excessive work as important in the regulation of biological parameters, such as lipid profiles,15 and psychological events as modulators of immune response.16 Other studies have evoked stress and fatigue as worsening factors for headaches and chronic CNS diseases, respectively.17-19

In summary, patients’ beliefs about factors triggering neurological disease only partially concur with medical opinion. If doctors paid particular attention to their beliefs when explaining the medical point of view regarding triggering of their disease, patients’ compliance with treatment could improve. A future development may be to repeat this study with patients with heart (coronary artery) diseases and compare the results with those of the present study. We would expect the results from such a study to be closer to those of our patients with CNS diseases than those of the patients with CNS diseases. Asking patients’ relatives the same questions could also provide new insights into patient care, as relatives often influence compliance with therapy. It should also be confirmed whether patients’ beliefs influence compliance—for example, in cerebrovascular risk factor follow up after stroke.

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