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Research Article
Poststroke Fatigue Is Still a Neglected Issue: Findings from an Internet-Based Study on the Need for Information and Treatment in The Netherlands

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Objective. To evaluate the need for information and treatment of poststroke fatigue (PSF) in community-dwelling patients with stroke in The Netherlands. Methods. Data were obtained from a Dutch internet-based questionnaire. The amount of information received about PSF, self-management and other treatment options, and the perceived need for treatment were scored. PSF was assessed with two Visual Numerical Scales of fatigue severity (VNSF), the Fatigue Severity Scale (FSS7), and by scoring the nature (physical versus mental) and onset time of PSF. Results. Data were available of 538 stroke survivors (mean age 52 years, 45% men, and mean time since onset 2.7 years). Severe fatigue (both VNSF items ≥7; 48%) and severe fatigue impact (FSS7 > 5; 68%) were frequent. Most participants (57%) experienced both physical and mental fatigue. Only 17% of the respondents indicated to have had received sufficient information about PSF and 7% about treatment options, whereas 56% expressed a substantial need for treatment. The need for treatment was moderately associated with fatigue severity and fatigue impact, whereas information status was not related to any demographical, fatigue, or stroke characteristic. Conclusions. PSF is a significant symptom after stroke requiring medical attention and treatment. The results of this survey indicate that patients do not receive adequate information on PSF.

1. Introduction
Persisting fatigue is a common and debilitating consequence of stroke even in patients with good recovery [1–4]. Prevalence rates of poststroke fatigue (PSF) are substantial, varying between 38 and 73% [4]. These rates seem to be stable over time, with no marked decline after the postacute stage to even years following the injury [5–9]. As no unequivocal associations with clinical or demographical variables, such as stroke type, age, sex, or education, have been found, all patients who have experienced a stroke may be at risk to develop this symptom [4]. Furthermore, PSF has been found to have a negative effect on quality of life [2, 10], rehabilitation outcomes [11], and even mortality [12–14]. However, PSF is often misdiagnosed [11, 15, 16] and evidence-based clinical guidelines for dealing with PSF are scarce [17, 18].

The pathogenesis of PSF is still poorly understood [4, 12, 19, 20] but believed to be multifactorial [4, 5, 12, 14, 20–22]. Although direct associations with biological markers
have been demonstrated only in a few studies [20], the brain damage itself is suggested to be a primary cause for the experienced fatigue [23–25]. Furthermore, associations with psychological distress such as depressive symptoms and anxiety have been repeatedly found [4]. The direction of this association has not been established, but somatic complaints seem to mediate this association [22]. Moreover, the consistent finding of double dissociations between these symptoms underscores the distinction between these syndromes [3, 22, 26]. However, psychological distress may certainly exacerbate fatigue and vice versa.

It has been accepted that PSF is a multifaceted phenomenon, including the severity of fatigue and the impact of fatigue on daily life [4]. Although no uniform definition of PSF exists, it is generally defined as "a subjective experience of extreme and persistent tiredness, weakness, or exhaustion after stroke, which can present itself mentally, physically or both and which is unrelated to previous exertion levels" [18, 27]. Since this definition is intrinsically subjective and no derivative assessment tools have been specifically constructed for patients with stroke, a large variety of fatigue rating scales have been used in research and clinical practice [20, 28]. Some of these tools assess the dimension of fatigue severity, such as Visual Analogue Scales [29] or the Checklist Individual Strength [30]. Others, such as the Fatigue Severity Scale, measure the impact of fatigue in daily life [31]. The assessment of both aspects is needed to comprehensively assess PSF and to warrant the comparability of different studies.

A few qualitative studies in small focus groups have demonstrated that patients with PSF report a great need for information on the syndrome [15, 16]. Patients reported that the lack of information led to confusion and distress, which in turn elongated the time needed to adjust to the fatigue [16]. They want to understand their experience of fatigue and have it diagnosed or explained so that they are less overwhelmed by it and know what to do about it [15]. Studies on the treatment of fatigue in patients with stroke and in patients with other neurological disease suggest that patient education, teaching energy conservation strategies, and graded activity training can be helpful in the management of fatigue [18, 32, 33].

Despite the importance of education and treatment for patients with PSF, little research has been conducted to quantitatively identify the need for education and treatment possibilities amongst stroke survivors [17, 18]. Furthermore, PSF is often not accurately recognized [11, 15, 16]. The aim of the present study was to investigate the current provision of patient information and healthcare in The Netherlands, by an internet-based questionnaire, and to relate these needs to demographic, fatigue, and stroke characteristics.

2. Methods

Data were obtained from a Dutch internet-based questionnaire. External links to the website were placed on the Dutch Wikipedia site about stroke and on the website of The Netherlands Brain Foundation (Hersenstichting). All participants who spontaneously completed the questionnaire consented with its use for scientific research. No feedback about results or financial reward was given and data were anonymously collected.

To identify current information and need status, questions about the amount of information received with regard to (i) PSF, (ii) self-management techniques, and (iii) treatment had to be answered on a 5-point Likert Scale (ranging from none to ample information) as well as the need for treatment of PSF (from none to a great need). The sum of the information scores was used (range 0–15) to indicate information status.

A Visual Numerical Scale was used to assess the severity of fatigue (VNSF). The VNSF consisted of questions about perceived fatigue severity (ranging from 0: no fatigue to 10: extreme fatigue) at present (question 1) and over the past 2 weeks (question 2). A score above 6 on both VNSF items was regarded as severe fatigue [34]. The mean of both items was used for statistical analysis.

The Fatigue Severity Scale-7 (FSS7) [21] is a well-validated tool to assess fatigue impact. It contains the last 7 items of the original 9-item FSS [31], to be scored on a 7-point Likert Scale from none to ample information (range: 1–7) [21, 31].

Additional questions about the nature of PSF (physical versus mental) and postonset time of fatigue had to be answered on a 5-point Likert Scale. Furthermore, data were collected regarding date of stroke, age, years of education, marital status, and employment. Questions on the assessment itself were posed last, with regard to the amount of help participants received during the assessment, the time needed to complete the questionnaire, and the perceived difficulty of the questionnaire.

3. Data Analysis

Double and faulty entries were identified by comparing demographic and stroke characteristics and subsequently discarded. Questionnaires not independently completed, were analyzed separately. Of all the correct entries, descriptive statistics were calculated. The association of information status, fatigue severity (VNSF), and fatigue impact (FSS7) with demographic data, age, sex, education, post-stroke time, onset time of fatigue, and nature of PSF was tested using Pearson’s correlation coefficient for continuous and χ²-tests for categorical variables. All analyses were conducted using SPSS version 18 for Windows, with Sidak correction for multiple analyses (alpha set at .004).

4. Results

Between April 2009 and June 2011 the website drew 9,204 unique visitors. The questionnaire was completed 575 times. Of these 538 could be included, since 33 respondents sent in multiple questionnaires and 4 participants had not had a stroke. Primary analyses were then performed on 479 questionnaires, since 59 entries indicated that they had been filled in with the assistance of another person (50) or had been completed by a proxy (9).
Table 1: Participant characteristics and correlations with VNSF and FSS7 (N = 479).

<table>
<thead>
<tr>
<th>Demographic and stroke data</th>
<th>Mean ± SD%</th>
<th>VNSF, r(P)</th>
<th>FSS7, r(P)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (y)</td>
<td>52.4 ± 10.8</td>
<td>−.15 (&lt;.001)</td>
<td>n.s.</td>
</tr>
<tr>
<td>Time since stroke (y)</td>
<td>2.73 ± 4.72</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Gender male</td>
<td>45%</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Education (y)</td>
<td>12.9 ± 2.5</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Living with partner</td>
<td>74%</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Currently employed</td>
<td>57%</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue severity (VNSF)</td>
<td>6.54 ± 1.85</td>
<td>.39 (&lt;.001)</td>
<td></td>
</tr>
<tr>
<td>Both VNSF scales ≥7</td>
<td>48%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue impact (FSS7)</td>
<td>5.52 ± 1.23</td>
<td>.39 (&lt;.001)</td>
<td></td>
</tr>
<tr>
<td>FSS7 &gt; 5</td>
<td>69%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PSF (VNSF ≥ 7 ) since:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prestroke</td>
<td>18%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td>53%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–6 months after stroke</td>
<td>19%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;6 months after stroke</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information and needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sum of information scores</td>
<td>5.87 ± 2.88</td>
<td>n.s.</td>
<td>n.s.</td>
</tr>
<tr>
<td>Information received on PSF*</td>
<td>n.s.</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>37%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>46%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td>17%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information on self-management*</td>
<td>n.s.</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>50%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>37%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td>13%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information on treatment*</td>
<td>n.s.</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>63%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need for PSF treatment*</td>
<td></td>
<td>.34 (&lt;.001)</td>
<td>.31 (&lt;.001)</td>
</tr>
<tr>
<td>Currently receives treatment</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No need</td>
<td>10%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>24%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Substantial</td>
<td>56%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Categories are combined to none (none), some (a little and some), and sufficient (sufficient and ample/a great need).

Table 1 lists the patients’ demographic and clinical characteristics, together with their information status and need for treatment, related to the scores on fatigue severity (VNSF) and fatigue impact (FSS7). Except for younger age, no associations between PSF and demographic variables were found.

Only 17% of the participants indicated they had received sufficient information about PSF and 7% felt they had received sufficient information about treatment options. In contrast, 54% of the respondents expressed a substantial need for treatment. Patients who had no need for treatment (11%) experienced less severe fatigue (VNSF: M = 5.0 ± 2.0) and reported less fatigue impact (FSS7: M = 4.8 ± 1.5) than those currently receiving treatment (VNSF M = 7.1 ± 1.8; FSS7 M = 5.6 ± 1.4) or those expressing some to substantial need (VNSF M = 6.7 ± 1.7; FSS7 = 5.5 ± 1.2, P < .001). The amount of need for treatment was associated with fatigue severity and impact, but not with any demographical or stroke variable (all P > .004). Information status was not related to any stroke, fatigue, or demographic characteristic (all P > .004).

The experienced nature of PSF on a physical-to-mental dimension differed greatly between participants χ²(4) = 55.33, P < .001, with 57% of the patients expressing both physical and mental fatigue components (Figure 1). No associations were found between the nature of PSF
However, patients who did not complete the questionnaire PSF. Only a small negative correlation with age was found.

Interestingly, fatigue scores were neither associated with sex or post-stroke time, nor with the onset time or nature of stroke, because most of the participants experienced the onset of fatigue within 6 months after stroke. Yet, pre-stroke fatigue was reported in about 10% of the participants with severe fatigue, while 71% experienced the onset of fatigue within 6 months after stroke.

5. Discussion

This internet-based study was conducted to evaluate the need for information and treatment concerning PSF in community-dwelling patients with stroke in The Netherlands. The results indicate that fatigue is still a neglected symptom after stroke, because most of the participants did not receive sufficient information about (the causes) of fatigue (83%), about self-management techniques (87%) or other treatment options (93%). This worrisome lack of information shows a remarkable contrast with the fact that 54% of participants indicated a substantial need for treatment for PSF.

A large proportion of the participants in the present study experienced severe fatigue as assessed with the VNSF (48%) and a severe fatigue impact as assessed with the FSS7 (69%). The moderate association between both scales reveals that different aspects of PSF were measured. Interestingly, fatigue scores were neither associated with sex or post-stroke time, nor with the onset time or nature of PSF. Only a small negative correlation with age was found. However, patients who did not complete the questionnaire independently were more severely fatigued and older than those filling in the questionnaires without assistance. These results emphasize the persistence of fatigue complaints after stroke, irrespective of when or by whom they are reported.

Most participants experienced fatigue both physically and mentally, which underscores the notion that PSF includes both components. The finding that the need for treatment was associated with fatigue severity and fatigue impact is understandable and emphasizes the importance of providing appropriate information. The result that the need for information itself was not associated with fatigue scores indicates that even patients with relatively mild fatigue should receive adequate information about PSF and its treatment options. It is possible that patients in fact have received information on PSF and treatment options, but due to their mental fatigue were unable to remember the information. In this case, the provision of information should be more adequately tailored to the fatigability and the use of written information such as leaflets could be of aid [35].

This study may have been subject to bias. Most importantly, especially participants with a great need for information and/or need for treatment can be expected to search the internet for information about PSF and its treatment options. As a result, figures about fatigue severity, fatigue impact, and lack of information may have been confounded by selection bias. On the other hand, 63% of the participants had received at least some information about PSF and 37% about treatment options. In addition, our respondents were relatively young (52 years of age), highly educated (>12 years), and 57% still were employed, suggesting preserved cognitive functions, which should have enabled them to receive and ask for appropriate information. Another limitation is that PSF scores may have been influenced by pre-stroke fatigue or fatigue as a result of concurrent disease(s) occurring after stroke. Yet, pre-stroke fatigue was reported in only 18% of the participants with severe fatigue, while 71% experienced the onset of fatigue within 6 months after stroke.

6. Conclusion

PSF is an important clinical symptom after stroke, requiring attention by medical professionals as well as treatment and/or care. It is, however, still a neglected phenomenon in The Netherlands.

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