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Boomsma, Maarten Michiel

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Comparison of Dutch and US patients' perceptions of the effects of Wegener's granulomatosis on health, function, income, and interpersonal relationships: comment on the article by Hoffman et al

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Arthritis and Rheumatism 1999;42:2495-7
To the Editor:

We read with great interest the article by Hoffman et al (1998), in which patient-perceived effects of Wegener's granulomatosis (WG) on health, function, income, and interpersonal relationships were reported. From this investigation it could be concluded that WG has a major impact on quality-of-life issues.

Some limitations of this study, however, were apparent. One of the major limitations was that the investigation was performed as a single-site study. Whether the results are also applicable to patients in other parts of the world is still unknown. We thus studied patient-perceived effects of WG in our patient population in Groningen and compared our findings with those obtained in the Cleveland study. The questionnaire that was used by Hoffman et al was translated into Dutch and sent to 91 WG patients who are regularly seen at the outpatient clinic of University Hospital Groningen. All patients met the American College of Rheumatology criteria for WG (Leavitt et al., 1990). Our study design was approved by the formal ethics review committee.

Seventy-nine of the 91 patients (87%) responded (Cleveland study 60 of 100 patients). Sixty-four of the 79 lived with a partner, and 59 of these (92%) also responded (Cleveland study 43 of 44 partners). Dutch patients were comparable with the Cleveland patients with respect to sex, age, race, median duration of disease, distribution of organ involvement, and patient-reported comorbidity.

The patient-reported delay from onset of symptoms to diagnosis of WG was, however, much shorter in the Dutch patients (mean 9.4 months versus 16.8 months in the Cleveland patients), possibly due to a greater awareness of WG in our region and hence more widespread use of the antineutrophil cytoplasmic antibody (ANCA) test. Interestingly, in a study of 35 patients (Cohen Tervaert et al., 1987) that was performed in 1986, at the time ANCA testing had only recently been introduced in our laboratory (van der Woude et al., 1985), we also found a longer delay in diagnosis (17.7 months), comparable with the delay reported by the Cleveland patients. Another observed difference between our patients and those reported by Hoffman et al was that the Dutch patients were less often told that their problems were "psychosomatic" (14% versus 25% of the Cleveland patients).

Patient happiness was equally effected by WG in The Netherlands and the US (32% Dutch patients unhappy versus 33% Cleveland patients), although somewhat fewer Dutch patients reported being depressed because of their disease (33% versus 43% of the Cleveland patients), and, additionally, fewer Dutch patients reported suicidal thoughts (7% versus 14% of the Cleveland patients).

Remarkably similar findings were found with respect to the impact of WG on employment status. Our patients missed work for long periods somewhat more frequently, and more patients worked a reduced number of hours. In The Netherlands, almost all patients changed duties at work (Table 1). Finally, 27% of our patients were disabled and receiving disability benefits (Cleveland patients 31%).
Table 1  Major differences between the Cleveland Wegener's granulomatosis (WG) patient population and the Groningen WG patient population

<table>
<thead>
<tr>
<th></th>
<th>Hoffman et al (1998) a</th>
<th>Boomsma et al a</th>
<th>Difference b</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact on financial security</td>
<td>28</td>
<td>5</td>
<td>5.6</td>
</tr>
<tr>
<td>Bring the family closer together</td>
<td>47</td>
<td>16</td>
<td>2.9</td>
</tr>
<tr>
<td>Relationship with partner improved</td>
<td>50</td>
<td>20</td>
<td>2.5</td>
</tr>
<tr>
<td>Relationship with partner worsened</td>
<td>18</td>
<td>9</td>
<td>2.0</td>
</tr>
<tr>
<td>WG causes suicidal thoughts</td>
<td>14</td>
<td>7</td>
<td>2.0</td>
</tr>
<tr>
<td>Concerned about long-term effects of WG</td>
<td>70</td>
<td>35</td>
<td>2.0</td>
</tr>
<tr>
<td>and treatment</td>
<td>37</td>
<td>90</td>
<td>0.4</td>
</tr>
</tbody>
</table>

a Values are percents.

b Differences of >1 indicate higher frequency among the Cleveland patients; differences of <1 indicate higher frequency among the Groningen patients.

The most remarkable differences between Dutch and American patients were found in the answers to questions pertaining to interpersonal relationships. Whereas 47% of the Cleveland patients thought that their illness brought their family closer together, only 16% of our patients thought so. Not only did fewer Dutch patients believe that their relationship with their partners improved (20% versus 50% of the Cleveland patients), but fewer Dutch patients also reported a worsening of their relationship (9% versus 18% of the Cleveland patients). Interestingly, the degree of agreement between patients and partners about the effect of the illness on their relationships was higher in our patient group than in the Cleveland group (observed agreement in The Netherlands 84.4%, chance agreement 53.8% [K = 0.66]; observed agreement in Cleveland 52.8%, chance agreement 35.5% [K = 0.27]).

Finally, partners of Dutch patients were less often concerned about the long-term effects of the disease and treatment (35% versus 70% of the Cleveland patients) and about implications of the disease on financial security (5% versus 28% of the Cleveland patients).

In conclusion, our study findings are consistent with those of Hoffman et al (1998) and demonstrate that WG is associated with substantial medical morbidity resulting in physical and occupational disability. Important differences, however, exist with respect to the influence of WG on interpersonal relationships. We hypothesize that most of these latter differences are due to cultural and socioeconomic differences between The Netherlands and the US.
Chapter 10

Literature


Patients' perceptions of the effects of systemic lupus erythematosus on health, function, income, and interpersonal relationships; a comparison with Wegener's granulomatosis

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Gary S. Hoffman ³, Jan Willem Cohen Tervaert ⁴

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Submitted for publication
Abstract

To describe the patients' perceptions of the effects of systemic lupus erythematosus (SLE) and Wegener's granulomatosis (WG) on health, function, income, and interpersonal relationships, 114 patients with SLE and 79 patients with WG completed a self-administered questionnaire. Patients had SLE or WG for a median period of 10 and 5 years, respectively. All patients experienced substantial functional morbidity. Two-thirds of the patients with SLE or WG reported either a periodic or permanent inability to perform daily activities at home and/or at work. Furthermore SLE as well as WG had a considerable impact upon the psychological and social life affecting their happiness, and altering relationships. Our study demonstrates that SLE and WG are associated with substantial medical morbidity resulting in physical and occupational disability. SLE has a profound impact on patients' lives, similar to that experienced in patients with WG.

Introduction

Systemic lupus erythematosus (SLE) is a multisystem autoimmune disease with significant morbidity and mortality. Survival of patients with SLE has increased greatly in the past 20 years (Urowitz et al., 1997; Blanco et al., 1998; Jacobsen et al., 1998). Early diagnosis and better treatment of the disease and its complications are the most likely explanations for the extended life span of most patients.

Although prolongation of life is of clinical importance, health status and quality of life are also important outcomes in SLE. Health status, quality of life, and the psychosocial impact of the disease in patients with SLE have been studied extensively by several groups (Burckhardt et al., 1993; Gladman et al., 1996; Hanly, 1997; Karlson et al., 1997; Liang et al., 1984; Stoll et al., 1997; Abu-Sakra et al., 1999; Da Costa et al., 2000; Thumboo et al., 2000). From these studies it can be concluded that quality of life is impaired in patients with SLE (Abu-Sakra et al., 1999; Da Costa et al., 2000). Several psychosocial, disease, and therapy related factors have been identified that influence quality of life (Burckhardt et al., 1993; Gladman et al., 1996; Hanly 1997; Karlson et al., 1997; Stoll et al., 1997; Thumboo et al., 2000). Some (Karlson et al., 1997; Stoll et al., 1997), but not all studies (Gladman et al., 1996; Hanly, 1997) have found that quality of life is related to disease activity or fixed organ damage. Studies estimating the socioeconomic impact of SLE are scarce (Thumboo et al., 2000). This is probably due to the many aspects associated with measuring the socioeconomic impact of a chronic disease.

Recently Hoffman et al (Hoffman et al., 1998) studied patient-perceived effects of Wegener's Granulomatosis (WG) on health, function, income, and interpersonal relationships, and concluded that WG has a major socioeconomic impact. WG and SLE are both multisystem autoimmune diseases which bare many similarities with respect to organ involvement and the course of disease. Furthermore, both diseases have been reported to be associated with significant mortality and morbidity (Hoffman et al., 1992; Urowitz et al., 1997; Blanco et al.,
Patients' perceptions of the effects of SLE and WG

1998; Jacobsen et al., 1998). Therefore we wondered whether the effects of SLE on patients' lives is similar to that experienced in WG. In order to study patients' perceptions of the effects of SLE and WG on health, function, income, and interpersonal relationships, we sent Hoffman's questionnaire to all of our patients with these diseases who attend our clinic in Groningen (the Netherlands), and compared the socioeconomic impact of SLE to WG.

Patients and methods

The original questionnaire was developed by Hoffman et al to assess health, social, and economic impact of WG from a patient perspective (Hoffman et al., 1998). The majority of questions were multiple choice questions (e.g. How would you rate the present impact of the disease (including side effects of therapy) on your ability to perform your daily activities at home/or at work?: 1. No effect (no loss of ability to do all thing you want to do), 2. Periodic effect (period of worsening that improved to normal or near normal following therapy), 3. permanent inability to do at least some usual activities at home or work (for example, inability to drive or inability to participate in a favorite sport)). Questions were divided into the categories: health, function, income, and interpersonal relationships. Patients could write down additional comments at the end of the questionnaire. A separate questionnaire was developed for "life-partners" or spouses, to solicit their views on patient's disease activity, effects of the disease on patient's function, and psychological status of partner and patient (e.g. From your current perspective, has your spouce's illness affected his/her relationship with other people?: 1. yes, 2. no, 3. not sure). The complete questionnaire can be found in the Arthritis & Rheumatism section of the American College of Rheumatology World Wide Web site at www.rheumatology.org. Thirty to 60 minutes are required to complete the questionnaires. Permission was obtained from Dr. Hoffman to translate this instrument for use in Dutch WG patients and to adapt the questionnaire for use in SLE patients. In the SLE questionnaire, minor adaptations were made with respect to questions regarding organ involvement (breathing tube, and intestine involvement were added in SLE, ear nose and throat (ENT) was replaced by heart involvement in SLE), treatment (trimethoprim / sulfa was replaced by hydroxychloroquine in SLE), medical interventions (ENT / eye surgery and lung / nerve / nasal biopsy were left out in SLE), and complications of the disease or its treatment (blindness was left out in SLE).

Patients older than 18 years with either SLE or WG who were followed at the outpatient clinic of the University Hospital Groningen, the Netherlands, were eligible. Patients with SLE had to fulfill at least four of the criteria as defined by the American College of Rheumatology for SLE (Tan et al., 1982). Patients with WG had to fulfill the American College of Rheumatology 1990 criteria for WG (Leavitt et al., 1990) and meet the definition for WG of the 1992 Chapel Hill Consensus Conference (Jennette et al., 1994). Furthermore, eligibility of WG patients required a positive test for PR3-ANCA (Cohen Tervaert et al., 1990) during an active phase of the disease, presently or in the past.
The questionnaires were mailed to 150 patients with SLE and 91 patients with WG who met these criteria. The authors requested that the patient and their partner had to complete their respective questionnaires independently and return their answers anonymously. Our institutional ethics review committee approved the study design.

**Statistical analysis**

Categorical quantities were compared using the Fischer’s exact test (2 rows and 2 columns) or Chi-square test (more than 2 rows and 2 columns), and the Mann-Whitney test (unpaired observations) or Wilcoxon matched pairs test (paired observations) were used for continuous quantities. Reliability between patient and spouse opinions was evaluated using a kappa statistic. The weighted kappa statistics is a chance-corrected measure of agreement that is equal to 0 if the agreement between patient and spouse is what would be expected based on chance alone, and equal to 1 if there is perfect agreement between patient and partner.

**Table 1** Features of patients with WG and SLE from patient-reported data

<table>
<thead>
<tr>
<th></th>
<th>Patients with SLE</th>
<th>Patients with WG</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responded / total patients</td>
<td>114 / 150</td>
<td>79 / 91</td>
<td>N.S.</td>
</tr>
<tr>
<td>Responded / total partners</td>
<td>84 / 84</td>
<td>59 / 64</td>
<td>N.S.</td>
</tr>
<tr>
<td>Mean age at diagnosis [range], years</td>
<td>31 [7 - 70]</td>
<td>52 [20 - 79]</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Mean age at questionnaire [range], years</td>
<td>44 [20 - 80]</td>
<td>60 [27 - 90]</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Gender (Male / Female)</td>
<td>17 / 97</td>
<td>44 / 35</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Diagnosis &lt; 2 years of presentation</td>
<td>64%</td>
<td>85%</td>
<td>0.0016</td>
</tr>
<tr>
<td>Mean delay diagnosis [range], months</td>
<td>37 [0 - 336]</td>
<td>10 [0 - 108]</td>
<td>0.009</td>
</tr>
<tr>
<td>‘Psychosomatic’ cause suggested</td>
<td>25%</td>
<td>14%</td>
<td>N.S.</td>
</tr>
<tr>
<td>Median disease duration [range], years</td>
<td>10 [1-46]</td>
<td>5 [0 - 25]</td>
<td>&lt;0.0001</td>
</tr>
</tbody>
</table>

N.S. = not significant.

**Results**

**Patient characteristics**

One hundred and fourteen of 150 patients with SLE (76%) and 79 of 91 patients (87%) with WG responded after one mailing. Patients were mainly Caucasians (94%). Eighty-four of the 114 patients (74%) with SLE lived with a partner, and all of these partners (100%) responded (WG: 59 of 64 partners (92%)). As could be expected, there were differences in age and gender between the SLE patients and the WG patients (Table 1). Patients with SLE were younger at the time of diagnosis and more often of female gender (P < 0.0001). Duration of disease (P < 0.0001) and patient-reported delay from onset of symptoms to diagnosis of the disease (P = 0.009) were longer in patients with SLE. Sixty-one percent of the SLE patients
and 51% of the WG patients reported consultation of at least 3 physicians before the diagnosis and initiation of treatment occurred (not significant = NS). During this period many patients were told that their problems were "psychosomatic" (14% WG patients versus 25% of the SLE patients; NS).

Organ involvement
Eighty-one percent of the SLE patients and 91% of the WG patients reported initial involvement of more than one organ system, and in 45% and 35% of the patients with SLE and WG, respectively, additional organ systems were eventually affected by the disease during follow-up. The distributions of organ involvement at presentation and during follow-up, as reported by the patients, are listed in Figure 1A-B.

![Figure 1](image1.png)

**Figure 1** Frequency of organ involvement in systemic lupus erythematosus (SLE) (A) and Wegener's granulomatosis (WG) (B) as reported by 114 patients with SLE and 79 patients with WG on the study questionnaire at presentation of disease and during follow-up.

Disease activity and effects on daily living
Sixty-six percent of the SLE patients and 68% of the WG patients judged their disease as inactive at the moment of answering the questionnaire. Two-thirds of both groups reported that their disease had either a periodic or permanent effect on their ability to perform everyday activities at present. Daily life was therefore to some extent compromised in most patients of both diagnosis groups (Table 2, Figure 2). Patients with SLE (mean score of patients 4.2, mean score of partners 4.8; P = 0.0013) felt that the disease had affected their daily living more severely than patients with WG (WG: mean score of patients 7.0, mean score of partners 6.8; NS). The agreement between patients and partners about patient reported effects on daily
living was somewhat higher in the WG patient group than in the SLE group (agreement in WG patients [K = 0.65], agreement in SLE patients [K = 0.57]; NS). However, two-thirds of the patients reported that their current health had improved at the time the questionnaire was answered, and that their disease had less influence on daily life than at the moment of diagnosis (Figure 2B).

**Table 2** Impact of WG and SLE on daily life

<table>
<thead>
<tr>
<th>Impact</th>
<th>SLE Patients, %</th>
<th>WG Patients, %</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not compromised</td>
<td>12</td>
<td>14</td>
<td>N.S.</td>
</tr>
<tr>
<td>Slightly compromised</td>
<td>35</td>
<td>42</td>
<td>N.S.</td>
</tr>
<tr>
<td>Moderately compromised</td>
<td>41</td>
<td>28</td>
<td>N.S.</td>
</tr>
<tr>
<td>Severely compromised</td>
<td>13</td>
<td>15</td>
<td>N.S.</td>
</tr>
</tbody>
</table>

N.S. = not significant.

**Figure 2** Distribution of scores of 114 patients with systemic lupus erythematosus (SLE) and 79 patients with Wegener’s granulomatosis (WG) who were asked to rate how much the disease had affected their daily life on a scale of 1 (no effect) to 10 (changed everything) at diagnosis (A) and at the moment of answering the questionnaire (B).

**Employment status**

Patients with SLE generally had a higher level of education than patients with WG (data not shown). Regarding the patients who had been employed for at least one year, remarkably similar findings between SLE and WG were found with respect to the impact of the disease on employment status. Patients frequently had been off work due to their disease. WG patients were off work for at least 6 consecutive weeks somewhat more frequently (80% versus 61% of SLE patients; P = 0.05). SLE patients, however, tended to be off work for longer periods. Eighty one percent of the SLE patients that were off work for six consecutive
Patients' perceptions of the effects of SLE and WG

weeks had not resumed work after 6 consecutive months (WG patients: 53%; NS). About half of the patients with SLE and WG had changed duties at work since they were first diagnosed. In (nearly) all patients this was due to the disease. Furthermore, patients often worked a reduced number of hours (56% of SLE patients versus 41% of WG patients; NS). SLE patients more often had to resign their job (23% versus 5% of the WG patients; P=0.05) due to their disease. Eighteen percent of SLE patients and 23% of WG patients (NS) reported an income reduction due to disease, and in 8-10% of the cases family members had to change their employment status. More than half of all patients were currently unemployed and one-fourth received disability benefits. In WG patients, the reason for being currently unemployed was more often "retirement" (SLE: 15% versus WG: 49%; P = 0.0001) and in SLE patients the reason was more often "to continue formal education programs" (SLE: 10% versus WG: 0%; P = 0.04), or "fear of loosing benefits" (SLE: 16% versus WG: 7%; P < 0.0001).

Emotional reactions

SLE and WG have a profound impact on patients' wellbeing. SLE and WG equally affected patient happiness (34% of SLE patients were unhappy because of the effects of illness versus 32% of WG patients; NS). Slightly more SLE patients reported being depressed because of their disease (47% versus 33% of the WG patients; NS), and more SLE patients reported suicidal thoughts (14% versus 7% of the WG patients; NS). Interestingly, some patients reported depressive thoughts although they stated that the disease had no, or even a positive effect on their happiness. No significant difference was noted between the number of patients and partners whom believed that SLE or WG had created problems with depression. However, the degree of agreement between patients and partners about patient reported depressive thoughts was, again, higher in the WG patient group than in the SLE group (agreement in WG patients [K = 0.84], agreement in SLE patients [K = 0.53]; NS).

Personal relationships

SLE and WG have a considerable impact on inter-personal relationships. About half of the patients reported that their illness had affected their relationships with people (SLE: 40% versus WG: 55%; P = 0.05). The disease had affected their relation with their family, friends, and their partner (Table 3). Some differences between SLE and WG patients were found in the answers to questions pertaining to interpersonal relationships. SLE patients more often thought that their illness improved their relationship with their friends (SLE: 20% versus WG: 7%; P = 0.04), and brought their family closer together (SLE: 25% versus WG: 16%; NS). No remarkable differences were seen in the numbers of SLE and WG patients that believed that their relationship with their partners improved or worsened (Table 3). No significant difference was noted between the number of patients and partners whom believed that SLE or
WG had affected their relationship. However, the degree of agreement between patients and partners about the effect of the illness on their relationships was slightly higher in WG patient group than in the SLE patient group (agreement in WG patients [K = 0.71], agreement in SLE patients [K = 0.47]; NS).

Table 3 Impact of WG and SLE on patient’s relationships

<table>
<thead>
<tr>
<th>Impact</th>
<th>SLE Patients, %</th>
<th>WG Patients, %</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bring the family closer together</td>
<td>25</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Driven family apart</td>
<td>12</td>
<td>10</td>
<td>N.S.</td>
</tr>
<tr>
<td>No effect on family</td>
<td>63</td>
<td>74</td>
<td></td>
</tr>
<tr>
<td>Relationship with partner improved</td>
<td>19</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>Relationship with partner worsened</td>
<td>8</td>
<td>9</td>
<td>N.S.</td>
</tr>
<tr>
<td>No effect on relationship with partner</td>
<td>73</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Relationship with friends improved</td>
<td>20</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Relationship with friends worsened</td>
<td>24</td>
<td>23</td>
<td>0.04</td>
</tr>
<tr>
<td>No effect on relationship with friends</td>
<td>56</td>
<td>70</td>
<td></td>
</tr>
</tbody>
</table>

N.S. = not significant.

Concerns

Partners of patients were asked whether they had disease-related concerns about the future. Up to one-third of the partners of SLE and WG patients were very concerned about the long-term effects of the disease and treatment, but only a minority of the partners had great concerns about implications of the disease on financial security (Table 4).

Table 4 Partners of WG and SLE patients

<table>
<thead>
<tr>
<th>Impact</th>
<th>SLE Patients, %</th>
<th>WG Patients, %</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial security:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not concerned</td>
<td>60</td>
<td>71</td>
<td></td>
</tr>
<tr>
<td>Somewhat concerned</td>
<td>27</td>
<td>24</td>
<td>N.S.</td>
</tr>
<tr>
<td>Very concerned</td>
<td>13</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Long-term effects of disease:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not concerned</td>
<td>11</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Somewhat concerned</td>
<td>55</td>
<td>61</td>
<td>N.S.</td>
</tr>
<tr>
<td>Very concerned</td>
<td>34</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Long-term effects of treatment:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not concerned</td>
<td>20</td>
<td>23</td>
<td></td>
</tr>
<tr>
<td>Somewhat concerned</td>
<td>54</td>
<td>48</td>
<td>N.S.</td>
</tr>
<tr>
<td>Very concerned</td>
<td>25</td>
<td>29</td>
<td></td>
</tr>
</tbody>
</table>

N.S. = not significant.
Discussion

Advances in medical care have transformed SLE and WG from diseases with a high mortality to conditions with serious chronic morbidity. In this study we describe the patients' perceptions of the effects of SLE and WG on health, function, income, and interpersonal relationships.

The response rate for the subjects from our clinic was remarkable. Seventy-six percent of the SLE patients and 87% of the WG patients responded after one mailing. This is very high compared to other studies, in which response rates vary from 14 up to 60 percent after up to two mailings (Liang et al., 1984; Hoffman et al., 1998). Due to the good response rate and due to the fact that disease activity was generally absent in the majority of patients in both groups, the primary bias of sampling sick patients, appears to have been minimized.

The results convey a sense of profound impact of disease upon the physical and occupational abilities of patients with SLE and WG. Two-thirds of the patients reported either a periodic or permanent inability to perform daily activities at home and/or at work. Two-thirds of the patients who had been employed for at least one year before diagnosis had been off work for at least 6 consecutive weeks due to their disease, and more than half of the patients had changed duties at work and/or worked reduced hours. These findings are comparable with those of Hoffman et al who studied WG patients in Cleveland, USA (Hoffman et al., 1998).

In SLE patients, Thomboo et al evaluated working status, defined as stopping work (temporarily or permanently), or a change in the nature or place of employment, or working part time as a result of the disease (Thumboo et al., 2000). Working status in this study changed in only 24% of the SLE patients. This was, however, a prospective study and only changes in working status during the study period of six months were noted. Our data also suggest that the illness has a marked financial impact on patients and their families. One-fourth of patients with SLE as well as patients with WG, received disability benefits, and one-fifth of the patients who had been employed for at least one year reported a reduction in income, as was also found in WG patients in the USA (Hoffman et al., 1998).

Finally, the disease has a considerable impact upon the psychological and social life of patients with SLE or WG. About one-third of the patients reported that the disease had affected their happiness and caused depressive thoughts. Half of the patients reported altered relationships with family, friends, and partners, suggesting isolation and conflict. However, < 12% felt that relationships between family members and partners had suffered, which was a very encouraging observation. These findings are in agreement with previous studies (Liang et al., 1984; Hoffman et al., 1998) that also reported altered relationships with family, friends and spouses in patients with SLE as well as patients with WG. In SLE patients, loss of social activity was significantly correlated with depression (Liang et al., 1984). Whether these findings are directly related to the illness is not clear. It has been demonstrated that psychological disturbances in patients with SLE may be the result of adjustment difficulties of being chronically ill or of life stresses not directly related to the illness (Rimon et al., 1988).
In our study, there were also patients who reported a positive effect on their happiness and improved relationships with family, friends, and partners as was also observed by Liang et al (Liang et al., 1984) and Hoffman et al (Hoffman et al., 1998). This suggests a reaffirmation of life organized around new priorities.

We observed striking differences in answers on several items scored at time of diagnosis compared to the present situation. In line with observations of Hoffman et al (Hoffman et al., 1998), the majority of patients reported that their current health had improved and that their disease had less influence on daily life than at the moment of diagnosis.

Overall, it can be concluded from this study that SLE and WG, both chronic rheumatic illnesses for which modern treatment has had a great impact on survival, still profoundly impact patients' lives. We have also demonstrated that these findings in WG patients in the Netherlands were similar to those of WG patients in the USA (Boomsma et al., 1999). WG has great socioeconomic impact, regardless of cultural background. Although unique differences in clinical features and treatment exist between WG and SLE, both illnesses have similar impact on life-functions and mood.

Apart from similarities shared by SLE and WG, important differences in the physical and occupational disabilities were also noted. These differences may be partly explained because SLE patients are younger and more often of female gender than patients with WG.

Our study has several limitations. The questionnaire was originally designed and later validated for use in WG patients (Hoffman et al., 1998). Although we provided several minor adaptations to make the questionnaire more suitable for patients with SLE, it was not possible to compare specific treatments (medical or surgical) between diseases because of inherent clinical differences and needs of patients (e.g. ENT in WG, serositis and hemocytopenia in SLE). Comparison of these items was further hindered by differences in gender and age of both groups. An additional issue that needs to be established is the validity, for instance the test-retest reliability, of the questionnaire.

Recently a study of Abu-Shakra et al revealed that in various aspects of life, patients with SLE have quality of life scores as assessed by the quality of life scale similar to those of healthy people suggesting that it is important to compare patients with SLE not only with other diseases, but also with healthy controls (Abu-Shakra et al., 1999). Unfortunately, we were unable to compare the results with that of healthy controls since our questionnaire is not applicable to healthy controls.

This was a single-site study that examined the cumulative impact of SLE and WG on health-related quality of life in a cross-sectional setting. Rather than evaluating the status of patients at multiple time points as was done in the study of Thumboo et al (Thumboo et al., 2000), the questionnaire was developed to assess the impact of the disease over the course of the illness.

With regard to disclosure of financial and personal information, the questionnaire was anonymous. Due to this anonymity, patient reported information pertaining medical issues like disease duration, delay between initial symptoms and diagnosis, and organ involvement
could not be verified. However, we felt that anonymity was a primary condition in order to get adequate response regarding psychosocial / mental health status, and income. Furthermore, medical issues were not the main focus of the questionnaire.

Comparison of the present study with previous studies involving SLE patients is difficult since the purpose for which the questionnaire was designed is different from, for instance, the Medical Outcome Survey (MOS) SF-36 (Stewart et al., 1988) which has been widely used in previous studies (Galdman et al., 1996; Hanly, 1997; Da Costa et al., 2000; Thumboo et al., 2000).

In conclusion, our study demonstrates that SLE and WG are associated with substantial medical morbidity resulting in physical and occupational disability. Minor differences, however, exist with respect to the influence of SLE and WG on patients and relationships with their families. We hypothesize that most of the latter differences are due to age and gender differences in SLE and WG. SLE, like WG, has a profound impact on patients' lives.

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Literature


