Reflex sympathetic dystrophy of the upper extremity—a 5.5-year follow-up

Part II. Social life events, general health and changes in occupation

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The aim of this retrospective long-term follow-up study was to describe the psychosocial aspects, such as social life events (SLE), around the causative event of reflex sympathetic dystrophy (RSD) and the psychological history of 65 patients, 3–9 years after RSD of the upper extremity. General health and long-term changes in occupation were assessed by means of a general health questionnaire (RAND-36) and a structured interview, respectively.

SLE, with a life-change unit rate more than 35, was present in 32 patients. A psychological (or psychiatric) history was found in 22 patients. In total, 60% of the patients had a SLE and/or a psychological history. The pain scores of the RAND-36 among RSD patients differed significantly from those of the control group. 17 patients changed occupation after RSD. Nearly 30% of the patients had to stop work for more than one year.

The results show a high coincidence between RSD and associated psychosocial disorders and this may play a role in intensifying and prolonging the symptomatology of RSD.

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Reflex sympathetic dystrophy (RSD) is a very complex clinical syndrome associated with pain, tenderness, swelling, limitation of range of motion, vascular instability and atrophic tissue changes (Kozin et al. 1981, Holder and Mackinnon 1984, Gibbons and Wilson 1992, Veldman 1995). A variety of terms and definitions have been used to describe this syndrome and focus attention on different aspects of it (Kozin et al. 1976, Lankford 1980, Goris 1985, Amadio et al. 1991, Jänig and Stanton-Hicks 1995). RSD may develop after a variety of incidents, but most frequent after trauma or surgery. The incidence of RSD varies widely, from 0.03% to 37% (Veldman 1995). RSD mainly affects women (Veldman 1995).

Little is known about factors that facilitate or promote the development of RSD. From a theoretical point of view, it has been hypothesized that social life events (SLE) and psychological or psychiatric problems might be facilitating factors in RSD (van Houdenhove 1986, van Houdenhove et al. 1992, Geertzen et al. 1994). Social life events may play a role as a life stress factor increasing nociception in RSD patients (van Houdenhove et al. 1992). In some studies, it is claimed that the psychogenic aspects are of significance concerning the pathogenesis of RSD (Zachariae 1964, Pollack et al. 1980, DeLeo et al. 1983). Boulu writes: "ne fait pas une algodystrophy qui veut" (not everybody can get RSD, even if he wants to) (Boulu 1985). In other studies, it is claimed that RSD patients develop behavioral and emotional changes as a result of RSD (Ecker 1984, Schwartzman and McLellan 1987, van Spaendonck et al. 1992). Thus, there seems to be a cause-effect dilemma.

Few studies have reported the long-term outcome after more than one year of RSD (Subbarao and Stillwell 1981, Bickerstaff 1990, Field et al. 1992, Bickerstaff and Kanis 1994, Inhofe and Garcia-Moral 1994). Most of these studies describe impairments. Disabilities and handicaps are mentioned only briefly. Vocational outcome is described in only two studies. One study was performed more than 15 years ago (Subbarao and Stillwell 1981), a recent study reported only 6 cases (Field et al. 1992).

The aims of this study were

1) to describe the presence of social life events at the time of diagnosis and the presence of psychological (or psychiatric) problems,
2) to evaluate the general health, using the RAND-36, and to compare the data with those in the literature, and
3) to describe the long-term changes in occupation of RSD patients.

Patients and methods

The reader is referred to Part I of this study concerning patient selection. The following information was extracted from the medical records: SLE, psychological and/or psychiatric history, the causative event and the occupation at the time of diagnosis. Possible SLEs in the time span between 3 months before and 1 month after the causative event were verified (Rahe 1972). All SLE values from the Social Readjustment Rating Scale with a life-change unit rate higher than 35 were scored. This scale is a hierarchy-list of 42 events, such as divorce, death of a partner or near family member, etc (Table 1). During a structured interview the patient's psychological or psychiatric history from 3 years before RSD was recorded and verified in the medical records. Only the patients who had been seeing a psychologist or psychiatrist were given a score. The use of drugs such as analgesics or psychopharmacons by patients at the time of our evaluation was also recorded.

Table 1. Social Readjustment Rating Scale of Rahe (1972)

Life changing event	LCU-values > 35[a]
Family	
Death of spouse	100
Divorce	73
Marital separation	65
Death of close family member	63
Marriage	50
Marital reconciliation	45
Major change in health of family	44
Pregnancy	40
New family member	39
Major change in arguments with wife	35
Personal	
Detention in jail	63
Major personal injury or illness	53
Sexual difficulties	39
Death of a close friend	37
Work	
Thrown out of work	47
Retired from work	45
Major business adjustment	39
Changed to different type of work	36
Financial	
Major change in financial status	38

[a] LCU is life-change unit.

All patients answered the 36 questions of the RAND 36-item Health Survey (RAND-36; Dutch version). The RAND-36[1], a short version of the "RAND Health Insurance Study Questionaire" is similar to the MOS SF-36 (van der Zee et al. 1993). The observer filled in the questionnaires. The RAND-36 has nine subscales: physical functioning (walking, stair climbing, running, ADL), social functioning (social contacts), role limitations (restriction of ADL due to physical problems), role limitations (restriction of ADL due to emotional problems), mental health, vitality, pain, general health perception and health change. These scores on the subscales of our patients are compared with the norm-scores of a population of 1063 persons selected from the register of a medium size city in the north of The Netherlands (van der Zee and Sanderman 1993).

The following information was also obtained in the structured interview: occupation and changes in occupation due to RSD, involvement in litigation concerning (re-)employment and/or the guilt question in the accident or operation resulting in RSD.

Statistics

Data analysis performed in SPSS/pc™ included descriptive statistics concerning demographics, psychosocial aspects, changes in occupation and litigation.

Data analysis was performed in CIA (Confidence Interval Analysis) version 1 to analyze the significance of the differences in scores on the RAND-36 subscales between RSD patients and norm-scores.

Results

Psychosocial aspects

SLE with a life-change unit rate more than 35 was found in 32 patients. The mean score of the SLE in these 32 patients was 51. The mean score of the SLE in all 65 patients was 25 (0–100; SD 28).

Psychological or psychiatric problems, at the time of the causative event, were found in 22 patients. These patients had been seeing a psychologist or psychiatrist for different reasons. 2 patients were still seeing a psychiatrist.

SLE or psychological (or psychiatric) problems, were present in 39 patients of whom 15 patients had both kinds. Drug dependency was found for psychopharmacons in 7 patients and for analgesics in relation to the RSD in 8.

Table 2. Changes in occupation between time of diagnosis and time of evaluation

		Employment at follow-up evaluation			
Employment at diagnosis		Employed	Housewife	Not working	Retired
Self-employed	(4)	2	2	–	–
Employed	(31)	22	6	1	2
Housewife	(26)	2	24	–	–
Not working	(4)	–	2	2	–
Total	(65)	26	34	3	2

Of the 65 patients, 48 (74%) did not change their occupation.

General health

RSD patients had significantly more pain compared to the norm-score (RSD group: mean 71, SD 26; norm score: mean 80, SD 26; $p < 0.05$). A higher score indicates better health. When our group of patients was divided into age groups identical with those in the literature, significant differences were only found in the 35–44 year age-group (n 12) for physical functioning, social functioning, role limitations (restriction of ADL due to emotional problems), pain and change in health compared to the norm-score (n 195; $p < 0.05$).

Changes in occupation

Occupation at the time of the diagnosis RSD and at the time of evaluation are summarized in Table 2. 42% of the patients were employed, and 40% were housewives. 17 patients had to change their occupation. 5 patients were unemployed, of whom 4 were due to RSD.

Among all patients, 31 did not or could not (housewives) stop work, while 19 patients stopped work for 12 months or more. At the time of the evaluation, 47 patients were working full-time (including the housewives) and 13 patients were working part-time of whom 10 became housewives (-men) or stayed home because they had lost their job and 3 returned to work partially. A full allowance was given to 9 patients (who all became housewives) and 1 patient received a partial allowance.

Because of a supposed provoking factor, an accident not caused by the patient or incorrect action by a medical doctor, 7 patients obtained legal advice and took action. 3 patients took legal action because of disagreement concerning the size and duration of the allowance. 6 patients consulted a legal advisor because they had just had a re-examination for disability compensation (Dutch: WAO) and received a smaller allowance.

Discussion

SLE or psychological problems, associated with RSD, were found in 60% of our RSD patients at the time of the causative event. Our findings suggest that these facilitating factors are more important than is generally believed (Lynch 1992).

SLE may play a role as a life-stress factor. It is likely that stress and anxiety increase nociception in RSD (van Houdenhove et al. 1992). Such an increase in nociception may have been the facilitating factor or at least a factor promoting RSD. We looked at SLE with a life-change unit higher than 35, although the cut-off point may be arbitrary. In our study, 32 patients had SLE (LCU>35) at the time of the causative event and 22 had a previous psychological and/or a psychiatric history. In total, 24 patients had one of these facilitating factors and 15 had both.

Lynch (1992) did not find, in the literature, enough support to conclude that RSD is a psychosomatic syndrome. The literature reviewed, showed serious methodological defects such as retrospective studies lacking control groups or poorly defined periods in which the life-events had taken place. In view of the methodological defects, she concluded that there was no evidence that life-events and/or personality traits play a role in the pathogenesis of RSD. Others found little evidence that preexisting psychological factors in adults may be associated with RSD (Bruehl and Carlson 1992). In our study we found, assessing the medical records, that SLE and the psychological history already existed at the time of diagnosis and were not the result of RSD.

The possible role of psychological factors in RSD may have important implications for prevention and therapy of RSD (van Houdenhove 1986). Our finding, that SLE (or psychological problems) occur at the onset of RSD, indicates that a psychological examination and, if needed, psychological treatment could be important for RSD patients. If psychological factors do not play a role in the etiology of RSD, they certain-

ly play a role in continuation of the pain and disability in this syndrome (Bruehl and Carlson 1992).

The results of the scores on the RAND-36 show that the patients in our study have significantly more pain. Pain seems to be the major problem in RSD patients, as reported earlier (Bruehl and Carlson 1992, Degood et al. 1993, Geertzen et al. submitted). All other 8 subscales show no significant differences from the norm-score. There is no satisfactory explanation of the significant differences in the 35–45 year age-group. The RAND-36 can be used in research like ours but the study group must be larger with larger age sub-groups, in order to compare the data adequately with the norm-data.

Changes in occupation may be considered as an indicator of recovery after RSD, in other words, as a part of regaining general health. Medical doctors working with RSD patients are often confronted with questions about when to start working again, occupational disability, working efficiency and/or allowances. The Dutch society of RSD patients has its own journal in which these items are dealt with (Nieuwsbrief). Our clinical impression, before this study, was that many RSD patients had medicolegal problems. An analysis of changes in occupation and litigation is of clinical importance. In our study, 10 patients were officially (partial) disabled and 17 had to change their occupation. 72% of our patients, including housewives, were working full-time. The only study which is comparable to ours is the one by Subbarao and Stillwell (1981). Of 125 patients, 77 answered the follow-up letters. 31% of the patients were retired or did not go back to the same work, 35% were officially disabled, 30% went back to their jobs and 49% of the female patients were able to do all the housework. It seems that fewer of our patients became disabled than 15 years ago. These numbers are not completely comparable because of the different social systems in the USA and The Netherlands. RSD remains a disabling disease, because nearly 30% of our patients had to stop work for more than 1 year. Compared to low back pain patients and headache patients, RSD patients have higher rates of unemployment and financial compensation, therefore RSD must be seen as a disabling disease (DeGood et al. 1993).

In this study, 7 patients received legal advice within 3 months after a diagnosis of RSD; 9 patients sought legal counselling only later on, mainly due to a new law in The Netherlands concerning the size and duration of the allowance and the physical re-examination with respect to this law. Subbarao and Stillwell (1981) reported that 24 (19%) of the 125 patients had a notation in their medical records regarding a lawsuit. In The Netherlands it is less common to put in a claim against a medical doctor or insurance company, although there is a tendency to claim more often.

Conclusion

RSD is associated with psychosocial disorders and these disorders can intensify and prolong the symptomatology of RSD. RSD patients experience significantly more pain than a control group, even 3–9 years after the initial diagnosis. There is a tendency for the employment situation of RSD patients to improve in the last decade, but RSD is still a disabling disease.

Prospective studies should be done to identify the factors that facilitate development and possibly promote the RSD syndrome.

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[1] This list can be acquired through the corresponding author.