Outcome measures for Complex Regional Pain Syndrome type I: an overview in the context of the International Classification of Impairments Disabilities and Handicaps

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Abstract

Purpose: To determine the availability of relevant and objective outcome measures concerning Complex Regional Pain Syndrome Type I (CRPS I) for Rehabilitation Medicine.

Method: Outcome measures were classified according to the International Classification of Impairments, Disabilities and Handicaps. For each outcome measure a description of concept, operationalisation into variables and instrument was given. We performed a PUBMED MEDLINE search (1980-1998) using the following keywords: complex regional pain syndrome, reflex sympathetic dystrophy, impairment, disability, handicap, (long-term) outcome and effect/efficacy.

Results: Most outcome measures were concentrated on impairments, whereas measures at the level of disabilities and handicaps, the most relevant levels for Rehabilitation Medicine, were mentioned in very few studies. Objective outcome measures were merely found at the level of impairment.

Conclusion: The results indicate a need for the development of relevant outcome measures at the level of disabilities and handicaps that can objectively measure treatment efficacy for CRPS I.

Introduction

Complex Regional Pain Syndrome Type I (CRPS I; also known as Reflex Sympathetic Dystrophy) is a poorly understood and not well defined symptom complex comprising a combination of sensory, trophic, autonomic and motor impairments [1,2]. The syndrome usually follows surgery or trauma, and is generally expressed in the extremities. In addition to the impairments, CRPS I can lead to serious disabilities in performing activities of daily life and handicap [3,4]. In the acute phase of CRPS I, pain in particular may constitute a major cause of disability and/or handicap, whereas during the later stages CRPS I-associated motor impairments, together with pain, are thought to bring about disabilities and/or handicaps [1,5,6]. The complex entity of CRPS I has often been investigated, leading, however, to confusing and conflicting results and theories about the aetiology and pathophysiology [7]. As the disease is not yet understood, plus the fact that each speciality has its own discipline-specific approach, a wide variety of treatments (more than 50) is found in literature [8]. As a consequence, numerous measures to determine treatment outcome have been described.

In the present paper, the numerous measures that are used to determine treatment outcome in CRPS I research and clinical practice will be classified. So far, one of the difficulties in interpreting reports on treatment efficacy in CRPS I, has been the (objective) quantification of patient findings and the lack of uniform measurement of treatment outcome [9,10]. Classification of outcome measures may not only be a useful tool to indicate the extent of the (obvious) inconsistency in defining treatment outcome in CRPS I research. The main aim of classifying outcome measures in the present paper is to determine whether relevant and objective outcome measures for Rehabilitation Medicine are available. It is clear that objective outcome measures are preferable to subjective outcome measures; the latter are more likely to endanger reliability and validity of measurements. As for the relevance of outcome measures: outcome measures are considered most relevant for Rehabilitation Medicine when they concern the goal of Rehabilitation, that is regaining and/or maintaining of functionality by decreasing the consequences of a disease [11,12]. Outcome measures concerning impairments are considered

less relevant for Rehabilitation Medicine, especially since the relation between the consequences of a disease is often found to be rather ambiguous [13-15].

The International Classification of Impairments, Disabilities and Handicaps (ICIDH) [16] is an often-used classification, in which three hierarchical levels of the consequences of a disease on everyday life of patients are distinguished. Outcome measures on the level of impairments, disabilities and handicaps concern the consequences of diseases at the level of the body, the person and the person as a social being, respectively. As for CRPS I, the consequences at the ICIDH level of impairments can be categorised into sensory impairments (e.g. neuropathic pain, allodynia, hyperalgesia, hypesthesia, anaesthesia, dysesthesia, hyperpathia), autonomic impairments (e.g. oedema, hyperhydrosis, skin colour change, change of temperature), trophic impairments (e.g. atrophy of skin, nails, muscles and bone), and motor impairments (e.g. dystonia, weakness, spasms, tremor, difficulty initiating movement, increased tone and reflexes, and increase of complaints after exercise) [8]. Disabilities associated with CRPS I are those directly related to the involved extremity (e.g. problems with getting dressed with upper extremity CRPS I or climbing stairs with lower extremity CRPS I) and general disabilities in daily functioning (e.g. slow performance of activities of daily living). Handicaps associated with CRPS I concern limitations in social functioning (e.g. alienation) and problems with role fulfilment (e.g. a grandmother with CRPS I cannot play with her grandchild), as a consequence of pain, other impairments or disabilities [17]. From this list of consequences it becomes clear that CRPS I encompasses all three levels of the consequences of a disease as described in the ICIDH). Although some discussion continues about the sometimes unclear distinction between the theoretical levels of the ICIDH [18,19], we consider the ICIDH framework useful to classify outcome measures in order to make a statement on availability of relevant and objective outcome measures for Rehabilitation Medicine.

Method and data sources

To obtain data, a PUBMED MEDLINE search (1980-1998) was performed using ‘complex regional pain syndrome’, ‘reflex sympathetic dystrophy’, ‘impairment’, ‘disability’, ‘handicap’,

‘(long term) outcome’ and ‘effect’ as keywords. The initial idea of only using randomised clinical trial studies and quasi-experimental studies was not feasible given the relatively small number of studies performed up till now. Therefore, non-experimental and transversal studies with descriptions of one or more outcome measures were also included. Only journal articles in the English or Dutch languages were used. Publications without MEDLINE abstract and studies with less than 8 subjects were excluded. To provide insight in the kind of research that is performed concerning CRPS I, we studied some characteristics of the publications used for classification of outcome measures.

To determine the success of treatment in a reliable and valid manner, well-defined and methodologically sound outcome measures are of major importance [20-22]. In general, an outcome measure can be considered methodologically sound when the theoretical definition of the outcome measure (at the conceptual level) is clearly operationalised into one or more variables [21]. Moreover, an appropriate instrument to assign a value to variables has to be chosen [21]. In this study, we represented each outcome measure in a scheme, in which the concept to be measured, the operationalisation of this concept into variable(s), and the instrument to assign a value to the variables were described. It was not our aim to take reliability and validity of measurements with different instruments into account. Each outcome measure was classified according to the three levels of a consequence of a disease (impairment, disability and handicap). The earlier described categorisation of impairments [8] was also applied in the tables.

Each publication was analysed to find information about concept, operationalisation of concept into variable(s), instrument and level of the ICIDH-classification of the described outcome measures. Almost identical descriptions of concept, operationalisation and/or instrument of two or more outcome measures in different publications were represented as one outcome measure to limit the size of the tables. In case the concepts of outcome measures in different publications were similar, but different operationalisations and/or instruments were described, the outcome measures were shown separately

Results

To provide insight in the kind of research that is performed concerning CRPS I, some characteristics of the studies were described (table 1). In addition to information about the first author and year of publication, studies were categorised as either transversal or longitudinal depending on the number of measurements. Transversal studies were categorised as either retrospective or prospective depending on whether measurements are done with data that already existed before defining the research questions or yet to be acquired data. Longitudinal studies were categorised as either experimental or non-experimental depending on whether the researcher actively intervenes in the research process or not. Specification of the type of treatment and research field, based on the first author, were presented, as well.

Insert table 1 about here

Outcome measure at the level of impairment

Sensory impairment

A variety of outcome measures at the ICIDH level of sensory impairments were found (table 2). However, only few of the earlier described familiar CRPS I-associated sensory impairments [8,23] were used as concepts of outcome measures. It is clear that the concept of pain is most frequently used in CRPS I research and practice.

Insert table 2 about here

Although there was general acceptance of pain as the main concept, operationalisation of this concept differed considerably (table 2). In some publications, pain was operationalised by simply describing the type [24] or location [9,10] of pain. Other operationalisations of the concept of pain were focussed on the level of pain, indicated by using the terms degree [25], score [26], intensity [10,15,27,28] or severity [27-29] of pain. Changes in the level of pain were indicated by usage of the terms decrease [30], change [31-33], relief [25,34,35] or reduction [32,36]. These

differences in operationalisation were not related to the design of the study. From a methodological perspective, it may be expected that pain was operationalised as changes in pain level in longitudinal studies and as pain level in transversal studies, which was, however, not consistently done. In general, operationalising pain was considered obvious and was not extensively described. In addition to pain, tenderness was the only other sensory impairment that was used as an outcome measure concept in more than one publication. As for the instruments to measure pain, it appeared that pain was mainly measured by scales and questionnaires and virtually no objective instruments were used.

Autonomic impairments

Autonomic impairments of CRPS I patients can be categorised as changes in temperature, changes in skin colour, changes in volume and changes in sweat secretion [8]. These four autonomic impairments associated with CRPS I have all been used as outcome measure concepts (table 3): a large variety of 'autonomic' outcome measures were found. Some authors consider autonomic impairments as a cluster of signs or symptoms, which was represented by conceptual umbrella terms, such as 'vasomotor instability' [29,37-39] or 'vasomotor changes' [32]. Most authors, however, did not use such umbrella terms. For clarity, the initial concepts of tumour [31], oedema [9,15,26,40] and swelling [10,25,27,29,37-39,41,42] were grouped as volume. Operationalisations shown in table 3 are original operationalisations and were not renamed. Of the autonomic impairments, (changes in) volume was clearly most often used as concept of outcome measures.

Insert table 3 about here

Operationalisations of the autonomic impairment concepts, as well as the instruments to measure autonomic impairments were not uniform. Part of the outcome measure operationalisations were expressed as a ratio of affected and unaffected side, whereas the other part only took the affected side into account. The three outcome measures at the bottom of table 3 were separated from the other outcome measures. This was done because they could

either be considered as an outcome measure with a general operationalisation of more than one of the four autonomic impairments [37-39,42,43], or because none of the four autonomic symptoms were mentioned specifically in the text [44].

Trophic impairments

Only few outcome measures at the level of trophic impairments were found (table 4). Nearly all of these outcome measures were used by highly specialised disciplines, such as Nuclear Medicine and Human Metabolism & Clinical Biochemistry.

Insert table 4 about here

Motor impairments

A large number of 'motor' outcome measures at the ICIDH level of impairments were found (table 5). Lack of unity in defining outcome measures was very obvious with motor impairments: concepts, operationalisation as well as instruments differed enormously. Studies mainly focussed on operationalisation and instruments mentioning the concept to be measured. Information about concepts had to be extracted from all sections of the publications, which made some interpretation unavoidable. In several publications [10,15,38,41,42] information about concepts could not be found.

Insert table 5 about here

Range of Motion (ROM) was the most frequently adopted operationalisation of motor impairment outcome measures. Measurement of active or passive ROM was not always specified. Moreover, ROM was not consistently measured in the same joints of upper or lower extremity. In one study [29] the instrument to determine ROM was not specifically mentioned, which forces one to make assumptions when trying to classify the different outcome measures.

Outcome measures at the level of disability and handicap

Relatively few studies expressed the outcome of a CRPS I treatment in terms of disability and/or handicap (table 6). Therefore, we decided to describe the outcome measures of these two levels together. Concepts as well as operationalisations of outcome measures were described in very different ways, although the majority of outcome measure concepts at the level of disabilities were related to occupation. Instruments to assess 'disability' and 'handicap' were scales and questionnaires.

Insert table 6 about here

Operationalisation into activity level categories in ordinal scales was not always consistent and scales or interviews sometimes contained items with different levels of abstraction [32,42] including some items at the level of impairments, which made interpretation of treatment outcome difficult. Some instruments (e.g. RAND-36 Questionnaire) contain items at both the level of disabilities and at the level of handicaps [45]. Topics of the structured interview were not always reported [9].

Discussion and conclusion

Level of impairments

Sensory impairments

The almost unanimous choice of pain as the main 'sensory' outcome measure concept may be attributed to the fact that pain is often described as the most unpleasant feature of CRPS I for the majority of patients [1,5,8,46,47]. The large variability of other sensory impairments between patients and the lack of valid and reliable instruments may also play a role in this choice.
An important aspect in the evaluation of pain that was not taken into account in any of the studies is that, in CRPS I, acute pain in early stages of the disease most likely changes into chronic pain in later stages. Acute and chronic pain can be considered as different clinical

entities [48], which may not involve the same dimensions [49,50]. Therefore, one has to carefully consider the moments of measurement and the choice for a specific instrument to determine long-term pain evaluation in CRPS I; not all instruments are designed to reflect these different dimensions of acute and chronic pain.

To clearly classify the numerous outcome measures, we tried to fit each outcome measure in the scheme of concept, operationalisation and instrument. With respect to the operationalisation of the outcome measure concept of pain, this gave rise to some difficulties because authors usually failed to present an explicit operationalisation. It appeared that the majority of authors consider pain as a clear-cut concept, thus making some interpretation unavoidable. We realise that one may ask whether ‘level of pain’ and ‘changes in level of pain’ are actually operationalisations of pain, but in these cases thorough analysis of the publications failed to provide more detailed information.

Pain clearly is a very complex and diverse concept that can be interpreted or classified in several ways [51]. In one publication, pain was operationalised as mechanical allodynia and spontaneous deep pain [32]. These operationalisations, however, are both discrete sensory impairments in the framework of the ICIDH. In contrast to this framework, in which pain is considered as one of the sensory impairments in CRPS I, pain can also be considered as a separate entity [10,52], that can be classified into several levels of abstraction: nociception, pain, suffering and pain behaviour [51,53]. Because pain is often described as the most unpleasant feature of CRPS I and especially since it is the impairment that particularly leads to disability (which can be described in terms of pain behaviour), one may consider this latter classification also applicable to classify the CRPS I outcome measures. Although we acknowledge that the ICIDH is not ideal to classify the concept of pain, there are two reasons why we think the ICIDH is the most suitable framework to classify the numerous outcome measures. First, pain clearly is not the only consequence of CRPS I; using this other classification would not do justice to the other impairments that are found in CRPS I. Second, pain is not present in all CRPS I patients [54,55]; about ten percent of the patients do not have pain, which makes the alternative classification not applicable to determine outcome for this part of the patient group.

Pain and other sensory impairments were usually measured by scales and questionnaires. A major disadvantage of these instruments is their subjective character [56,57]. Another problem with measuring pain in CRPS I is that pain of individual patients can change often during the day and the pain level between patients can also vary widely [58]. The instruments to measure pain are not capable of detecting variation in pain level throughout the day. A possibility to overcome these problems is to evaluate 'pain behaviour' in addition to pain as a sensory impairment [51,53,59], especially because latest technological developments provide possibilities to objectively measure pain behaviour [60]. For Rehabilitation Medicine, measuring the concept pain behaviour operationalised as (changes in) the activity pattern is more relevant than measuring pain alone because pain behaviour is an outcome measure at the ICIDH level of disability and not at the level of impairment.

Autonomic impairments

It is clear that the number of 'autonomic' outcome measures by far exceeds the number of other outcome measures at the level of impairments, with the exception of pain. The popularity of 'autonomic' outcome measures together with 'sensory' outcome measures may be related to the current ideas concerning aetiology and pathophysiology of CRPS I. Sensory and autonomic impairments represent the most important features of an inflammatory reaction (dolor, calor, rubor and tumor) which are thought to play a role in the acute phase of CRPS I [55,61]. The acute phase is the focus of the majority of CRPS I studies. However, the greater part of CRPS I patients in Rehabilitation Medicine in the Netherlands are already in the later stages of the disease, which makes autonomic outcome measures less relevant for determining treatment efficacy.

Autonomic outcome measures are frequently measured by subjective purpose-formulated scales or questionnaires, although objective instruments are available [15,27,32,34,38,39,62].

Trophic impairments

Trophic impairments are not often used as outcome measures. This may be because these impairments are only found in a minority of CRPS I patients [43,55] which makes 'trophic' outcome measures a less logical choice. Even though objective measurement is trophic impairments is possible, a major disadvantage is that instruments are usually costly and not always available. Moreover, objective measurement requires trained personnel. Trophic impairments are generally measured for diagnosis of CRPS I and not to determine the effect of a treatment, although some authors have investigated the possibilities of using them as outcome measures [63]. It was concluded that the bone scan could be part of an algorithm rather than a discrete outcome measure. Trophic impairments are closely related to autonomic impairment; changes in the nutritional state are one of the consequences of changes in local blood flow, which, for some researchers, may make use of these measures redundant.

Motor impairments

Whether active Range of Motion (AROM) or passive range of motion (PROM) was measured was not always clear. This is a very important issue, however, because measuring PROM is assumed to be not appropriate for patients with CRPS I since the pain threshold is generally reached quickly [58]. In addition, ROM measurements in CRPS I patients are subject to considerable variation [64], which may have an impact on the objectivity and reliability of measurements. This is also true for grip strength: it was found that for objective medical reports on hand muscle strength, it is recommendable to measure three times in more than one session and, if possible, by more than one person [65]. In the studies that used grip strength as an outcome measure, only few actually used a (potentially) objective method [15,38,39,41,42]. In only one of these studies [15] was information presented about repeated measurement.
Even though motor impairments form a well-known aspect of CRPS I, epidemiological data on this matter are still scarce [6]. Whether this is a matter of lack of interest or lack of objective, reliable and valid instruments is not clear. However, it may be that researchers usually focus on

the early stages of CRPS I, whereas motor impairments become more obvious in the later stages.

Sum scores

In order to indicate the 'overall' condition of patients, in several studies, scores were assigned to a number of outcome measures and added to sum scores called Reflex Sympathetic Dystrophy-score [15,40], also Reflex Sympathetic Dystrophy-score [25,31] or Shoulder Hand Syndrome-score [66]. Reflex Sympathetic Dystrophy (RSD) and Shoulder Hand Syndrome (SHS) are two of the numerous names that are used to describe the disease. In the present study, we decided to use the term CRPS I because this is the term the International Association for the Study of Pain recently agreed upon [67]. Sum scores were made up of a varying numbers of outcome measures that usually had different relative contributions to the total score. This may be related to the discipline involved (e.g. ROM is more important to a rehabilitation specialist or an orthopaedist, whereas changes in temperature may be more relevant for an anaesthesiologist). In these 5 sum scores, pain was generally considered (one of) the most important concept(s) of outcome measures. In the selection of other outcome measures, however, little consistency in order of importance was found which makes interpretation of treatment outcome and comparison of different studies very complicated. An additional sum score, the Impairment level Sum Score (ISS)[58], was published after the initial MEDLINE-search. In this weighted sum score, pain is also the most important outcome measure concept.

Since the consequences of CRPS I encompass all three levels of the ICIDH, assessing treatment outcome by sum scores of different outcome measures at different ICIDH levels can be considered as a logical strategy. However, with the exception of the variable VAS-ADL in one of the RSD scores [15,40] and the affective and evaluative variables of the McGill Pain Questionnaire in the Impairment level Sum Score [58], all of the variables in these scores were exclusively on the level of impairments. Variability among patients regarding the functional impact of various impairments was reported as a reason to solely focus on the level of impairments [58].

Level of Disabilities and Handicaps

The small number of 'disability' and 'handicap' outcome measures that were found, were assessed by means of scales and questionnaires; no objective instruments were used. About half of the outcome measures at the level of disability and/or handicap were employed by researchers in the field of Rehabilitation (table 1). Apparently, outcome measures at these levels are also considered relevant by researchers in other research fields. With the exception of two studies [27,68], all studies in which outcome measures at the ICIDH level of disabilities and/or handicaps in CRPS I research were used are written in the last few years. This may also be related to increasing general recognition that the evaluation of treatments should include assessment of a broad set of outcome measures that are important to patients, especially functionality (level of disabilities), role performance (level of handicaps) and quality of life [69-72]. Clearly, assessing treatment outcome at the level of disabilities and/or handicaps is difficult: particularly when it comes to objective outcome measures. In one study [73], it was mentioned that the outcome measures 'increase in hours of sleep' and 'increase in physical activity' were taken into account. However, the authors failed to report on these outcome measures, which may also indicate that objectively assessing outcome at these two levels is considered relevant but difficult.

General discussion and conclusion

The aim of the present paper was to determine the availability of relevant and objective outcome measures concerning CRPS I for Rehabilitation Medicine. It appears that there clearly is a gap in the availability of these measures. Gaps in availability of appropriate outcome measures may be the starting point for the development of new instruments that are capable of objective measurement at the higher levels of the ICIDH. This does not implicate that we consider outcome measures at the level of impairment irrelevant for Rehabilitation Medicine. These outcome measures would be very relevant if there were an unambiguous relationship between impairments and changes in functionality; no clear evidence for such a relation in CRPS I has

yet been found. Studies investigating whether patients benefit from treatment in terms of improvement of functional health require disability and/or handicap measures [74]. Insight into a patient's disabilities and handicaps is also important for the choice of treatment.

For this overview of outcome measures used in CRPS I research and clinical practice, 30 publications were analysed. It was not our intention to be fully exhaustive: we omitted studies with small patient numbers because these studies usually report on preliminary results of employment of 'new' outcome measures. Classifying these outcome measures may result in an overview of one-time employed outcome measures, which was not the objective of this study. In the data selection we did not perform cross-referencing because we think that the outcome measures currently classified are representative for the outcome measures applied in CRPS I research in general. In our opinion, cross-referencing would not have added many other outcome measures; it would merely result in a larger number of references in the Reference No. columns in tables 2-6. Again, it was not our intention to be fully exhaustive.

The clinical picture of CRPS I has been described by authors from different clinical disciplines, such as anaesthesiologists, hand surgeons, orthopaedists, psychiatrists, and rheumatologists [7]. These different disciplines have not unexpectedly emphasised different signs, symptoms, diagnostic criteria, treatments and outcome measures, which may be a reason for some of the difficulties in reviewing the literature on CRPS I. The fact that little controlled research on CRPS I is done from the perspective of Rehabilitation [75] may have contributed to the lack of relevant outcome measures at the level of disabilities and/or handicaps. On the other hand, all disciplines should attempt to determine whether patients benefit from treatment in terms of improvement of functional health.

Due to the lack of consensus about pathogenesis, current treatments do not always have a rational basis [8]; this may have had an impact on the selection of outcome measures for determining treatment efficacy. Ideally, the selection of certain outcome measures depends on the questions to be answered in different studies [74]; namely, whether the treatment has a biological effect or a clinical effect. Research and treatment of CRPS I may still be in an early experimental phase, despite the amount of research that has already been performed. For studies on pathogenesis, impairment outcome measures probably are the best choice. Clinical

decision making can be improved by measuring at the level of disability, however, because these measures provide important and patient relevant information on whether a treatment improves the patient's functional health. Moreover, expressing outcome in terms of disabilities and handicaps, in addition to impairments, facilitates communication between disciplines and between specialists and patients.

In summary, classification of outcome measures in CRPS I research according to the hierarchical levels of the ICIDH shows that the majority of outcome measures describe treatment success at the level of impairment. Little consistency was found in concepts, operationalisation of these concepts into variables and the instruments used. Outcome measures at the levels of disability and handicap, the most relevant levels for Rehabilitation Medicine, were mentioned in only very few studies. Objective outcome measures were merely found at the level of impairment. The shortage of relevant and objective outcome measures can not be due to lack of interest in such outcome measures or in CRPS I. This finding calls for development of relevant outcome measures that can objectively measure treatment efficacy at the level of disabilities and handicaps. Recent developments in the field of ambulatory activity monitoring [76,77] seem to offer good perspectives.

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Captions of tables

Table 1: Overview of several aspects of the publications studied.

Table 2: Outcome measures used in CRPS I research to measure sensory impairments. Insufficient descriptive detail in publications is represented by a question mark.

Table 3: Outcome measures used in CRPS I research to measure autonomic impairments. Insufficient descriptive detail in publications is represented by a question mark. The bottom three rows represent outcome measures that do not fit into the categories of Kurvers (1997).

Table 4: Outcome measures used in CRPS I research to measure trophic impairments. Insufficient descriptive detail in publications is represented by a question mark.

Table 5: Outcome measures used in CRPS I research to measure motor impairments. Insufficient descriptive detail about concepts in publications is represented by a question mark.

Table 6: Outcome measures used in CRPS I research to measure disabilities and handicaps. Insufficient descriptive detail in publications is represented by a question mark.

(table 1)

Author(s) (+Ref. no.)	*Year*	*Design^*	*Subjects (n)*	*Type of treatment*	*Research field*
Atkins et al.[39]	1990	tran., pros.	60	no treatment	Orthopaedic Surgery
Bickerstaff et al.[41]	1991	long., exp.	20 (+20 control)	nasal calcitonine (Sandoz Basle)	Hum. Metabolism & Clin.Biochemistry
Bickerstaff et al.[42]	1994	long., non-exp.	274	no treatment	Hum. Metabolism & Clin.Biochemistry
Braus et al.[66]	1994	long., exp.	36	oral corticosteroids (methyl prednisolone) + daily physical therapy	Neuropathology
Cortet et al.[30]	1997	long., exp.	23	intravenous 2nd generation biphosphonate pamidronate (APD)	Rheumatology
Davidoff et al.[10]	1988	long., exp.	17	exercise program (8 weeks) + corticosteroids or sympathetic blockade	Rehabilitation Medicine
Field et al.[37]	1992	long., exp.	55	intravenous regional anaesthesia + cast immobilisation (4 weeks)	Orthopaedics
Field et al.[38]	1993	long., exp.	17	serial regional intravenous guanethidine blockade	Orthopaedics
Geertzen et al.[40]	1994	long., exp.	26	regional intravenous ismelin blocks (n=13) + radical scavenger DMSO (n=13)	Rehabilitation Medicine
Geertzen et al.[15,45]	1998	tran., retro.+ pros.	65	no particular treatment (follow-up after various treatments)	Rehabilitation Medicine
Gobelet et al.[9]	1991	long., exp.	33 (+33 control)	physical therapy combined with calcitonine	Rehabilitation Medicine
Hamamci et al.[26]	1996	long., exp.	24 (+16 control)	intramuscular salmon calcitonine treatment	Rehabilitation Medicine
Hassenbusch et al.[32]	1996	long., exp.	30	peripheral nerve stimulation	Neurosurgery
Hord et al.[34]	1992	long., exp.	12	intravenous regional bretylium and lidocaine	Anaesthesiology + Orthopaedics
Kaplan et al.[33]	1996	long., exp.	53	intravenous regional guanethidine Bier block	Anaesthesiology + Pain Management
Kozin et al.[78]	1981	tran., pros.	48 (+16 control)	no particular treatment	Radiology
Langendijk et al.[25]	1993	long., exp.	37	dimethylsulfoxide DMSO (50%) in a fatty cream	Pharmacy
Mailis et al.[62]	1997	long., exp.	15 (+21 control)	intravenous administration of sodyum amytal, a medium action barbiturate	Pain Investigation Unit
Muramatsu et al.[29]	1998	long., exp.	17	Movelat cream manipulation (MIRA) therapy and regional anesthesia	Orthopaedic Surgery
*Poplawski et al.[27]	1983	tran., retro.+ pros.	62	no particular treatment	Orthopaedics
*Poplawski et al.[27]	1983	long., exp.	27	regional intravenous block (+corticosteroids) followed by physical therapy	Orthopaedics
Ramamurthy et al.[28]	1995	long., exp.	30 (+30 control)	intravenous regional block with guanethidine	Anaesthesiology
Rauck et al.[36]	1993	long., exp.	26	epidural clonidine	Anaesthesiology
Robaina et al.[73]	1989	long., exp.	35	transcutaneous electrical nerve stimulation + spinal cord stimulation (n=6 of 35)	Neurosurgery + Anaesthesiology
Schwartzman et al.[24]	1997	tran., retro.	29	transthoracic or lumbar sympathectomy	Neurology
Subbarao et al.[68]	1981	tran., retro.+ pros.	77	no particular treatment (follow-up after various treatments)	Rehabilitation Medicine
Tu et al.[44]	1994	tran., pros.	8	surgical sympathectomy	Radiology
Vande Streek et al.[63]	1998	tran., pros.	?	no treatment	Nuclear Medicine
Veldman et al.[35]	1995	long., exp.	71	injection of bupivacaine + methylprednisolone for RSD shoulder complaints	Surgery
Zuurmond et al.[31]	1996	long., exp.	16 (+15 control)	dimethylsulfoxide in a fatty cream	Anaesthesiology

^ long.= more than one measurement, tran.= one measurement, retro.= data already available, pros.= data yet to be aquired, exp.= active intervention, non-exp.= no active intervention
* The study of Poplawski et al. consists of two parts with distinct designs that are shown separately.

(table 2)

Concept	*Operationalisation*	*Instrument(s)*	*Reference No.*
pain	burning pain	Visual Analogue Scale (VAS)	24
pain	change in level of diffuse pain	Visual Analogue Scale (VAS)	31
pain	change in level of diffuse pain	examination: pressure exerted over tendons	35
pain	change in level of mechanical allodynic + spontaneous pain	Verbal Digital Scale (0-10)	32
pain	change in level of pain	Verbal Digital Scale (0-10)	30
pain	change in level of pain	Visual Analogue Scale (VAS)	25,30,34
pain	change in level of pain	4-point scale	33
pain	change in level of pain	question(naire) or patient's estimate	32
pain	change in level of sensory, affective + miscellaneous pain	McGill Pain Questionnaire (PRI)	36
pain	level of pain	Visual Analogue Scale (VAS)	10,26,36,40,47,73
pain	level of pain	McGill Pain Questionnaire	28,73
pain	level of pain	3,4 or 6-point scale	27,29,66
pain	presence or absence of pain	question(naire) or patient's estimate	39,41,42
pain	joint pain (at rest or during movement) by palpation	4 or 5-point score	9,10
pain	affective, sensory + evaluative aspects pain	McGill Pain Questionnaire (PRI+NWC)	10
pain	pain as part of general health	RAND-36 Questionnaire	79
hyperalgesia	intensity of hyperalgesia	6-point scale	66
tenderness	tenderness of wrist, MCP, PIP, DIP	investigation	26
tenderness	bony tenderness in response to load compared to other hand	Dolorimeter ratio (kg/m^2)	37-39,41,42
?	moving two-point discrimination volar tip thumb+index finger	Disk Discriminator (mm)	79

(table 3)

Concept	*Operationalisation*	*Instrument(s)*	*Reference No.*
skin temperature			
calor	elevated skin temperature compared to other side	dorsal side observer's hand + patient's estimate	25,31
?	bilateral skin temperature	?	28
vasomotor instability	abnormal temperature affected hand	2-point questionnaire	42
calor	2-point temperature profile skin compared to other side	?	10
vasomotor instability	(7-point) temperature profile skin compared to other side	portable thermography	32,38
?	skin temperature response (to electrical stimulation)	thermometer	34,62
skin colour			
discoloration	difference in skin colour compared to other side	3-point scale	15,40
rubor	difference in skin colour compared to other side	observation/examination	25,31
vasomotor tone changes	change in skin colour compared to other side	examination on 4-point scale	32
vasomotor instability	abnormal skin colour affected hand	2-point questionnaire	42
volume			
volume	diffuse edema	observation/examination	31
volume	degree of oedema compared to other side	observation	25
vasomotor tone changes	degree of swelling compared to other side	observation	32
volume	degree or severity of oedema dorsal side throughout day	4-point scale	29
autonomic problem	degree or severity of distal oedema	4-point scale	66
volume	degree or severity of oedema	3 or 4 point scale (examination)	9,15,26,40
volume	volume hand compared to other side	ratio water displacement (+ assessment)	10,37-39,41,42
volume	digital circumference compared to other side	arthrocircameter or measuring tape	15,27,38,39
volume	skin thickness compared to other side	skinfold calipers on dorsum hand (mm)	39
perspiration			
vasomotor instability	hyperhidrosis affected hand	2-point questionnaire	42
?	hyperhidrosis affected hand compared to other side	observation	25
?	bilateral electrodermal activity from sweat glands	electrical stimulation and macroelectrode recording	62
vasomotor instability	response to external factors/environmental changes	questionnaire	37-39,42
?	assymmetrical blood flow in extremities	scintigraphy	43
vasoconctrictor tone	blood flow distal artery muscle affected side	colour duplex Doppler ultrasound	44

(table 4)

Concept	*Operationalisation*	*Instrument(s)*	*Reference No.*
trophic changes	degree of trophic changes	examination, 4-point scale	32
?	abnormal hair or nail growth compared to other side	observation	25
skeletal changes	trabecular bone evaluation	radiographic scoring system	41
skeletal changes	cortical bone evaluation of metacarpals	morphometry	41
skeletal changes	bone mineral density compared to other side	Nuclear Data ND 1100 scanner	41
dynamic boney changes	periarticular bone uptake compared to other side	Three-Phase-Bone-Scan (TPBS)	63
osteoporosis	demineralisation	radiography	43
?	increased periarticular activity compared to other side	scintigraphy	43

(table 5)

Concept	*Operationalisation*	*Instrument(s)*	*Reference No.*
loss of motor function	pinch grip, elbow flexion and shoulder abduction	Motricity Index	26
weakness	grip strength compared to other side	hand held strength gauge	41,42
joint function	grip strength compared to other side	sphygmomanometer	39
?	grip strength compared to other side	dynamometer	15,38
motor deficits	degree of motor weakness	4 or 6-point scale, examination	32,66
?	stiffness in fingers	questionnaire	41,42
loss of motion	stiffness during day	4-point scale on palpation or complaints	27,29
functio laesa	limited active ROM	observation/examination	31
inflammatory symptom	limited active or passive ROM shoulder	observation/examination	35
motor function	painless passive ROM shoulder	4-point scale with goniometer	66
motor function	passive ROM shoulder, wrist and MCP	goniometer	26
contracture	ROM PIP joint, severity compared to other side	4-point scale	29
joint function	ROM shoulder, elbow and finger	clinical assessment and goniometry	39
joint mobility	ROM fingers	goniometry	37
loss of mobility	ROM compared to other side	4-point mobility scale	9
stiffness	ROM all finger joints compared to other side	goniometer	38
loss of motion	ROM digital joints compared to other side	goniometer	27,28
motor function limitation	ROM fingers when making fist compared to other side	measurement tape	15,40
motor function limitation	ROM thumb	6-point scale	15,40
motor function limitation	active ROM shoulder+elbow+wrist compared to ROM normal ADL	goniometer	15
?	active ROM compared to other side	measurement tape and goniometer	10

(table 6)

Concept	*Operationalisation*	*Instrument(s)*	*Reference No.*
Disability			
activity level	rating of restriction of activities of daily living related to full-time job (100%)	11-point scale	32
status of daily activities	improvement in certain daily activities	interview 3rd party	32
daily activities	difficulties with using hands last 24 hrs (in upper extremity CRPS)	Visual Analog Scale (VAS) All Daily Activities	40
hand function	among others: restriction of everyday activities + performing simple tasks	de Bruijn (1987) scoring system	42
vocational or educational status	changes in vocational or educational status compared to premorbid level	questionnaire	68
work status ?	ability to perform occupational activity or ADL after 8 weeks of treatment	analysis/interview	9
employment status	changes in job and/or working time compared to prior CRPS	questionnaire, interview	27
occupational status	long-term changes in occupation	structured interview, 4 categories	45
Handicap			
functional social activity level	subjective grade of ability to return to premorbid levels	questionnaire	68
general health status	9 subscales (e.g. social functioning, role limitation, pain, mental health)	RAND-36 Questionnaire	45