Dutch Dataset Pain Rehabilitation in daily practice

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ORIGINAL ARTICLE

Dutch Dataset Pain Rehabilitation in daily practice: Content, patient characteristics and reference data

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Abstract

Background: No core set of measurement tools exists to collect data within clinical practice. Such data could be useful as reference data to guide treatment decisions and to compare patient characteristics or treatment results within specific treatment settings.

Methods: The Dutch Dataset Pain Rehabilitation was developed which included the six domains of the IMMPACT core set and three new domains relevant in the field of rehabilitation (medical consumption, patient-specific goals and activities/participation). Between 2010 and 2013 the core set was implemented in 32 rehabilitation facilities throughout the Netherlands.

Results: A total of 8200 adult patients with chronic pain completed the core set at first consultation with the rehabilitation physician. Adult patients (18–90 years) suffering from a long history of pain (38% >5 years) were referred. Patients had high medical consumption and less than half were working. Although patients were referred with diagnosis of low back pain or neck or shoulder pain, a large group (85%) had multisite pain (39% 2–5 painful body regions; 46% >5 painful body regions). Scores on psychosocial questionnaires were high, indicating high case complexity of referred patients. Reference data for subgroups based on gender, pain severity, pain locations and on pain duration are presented.

Conclusions: The data from this clinical core set can be used to compare patient characteristics of patients of other treatment setting and/or scientific publications. As treatment success might depend on case complexity, which is high in the referred patients, the advantages of earlier referral to comprehensive multidisciplinary treatment were discussed.

Significance: A detailed description of case complexity of patients with chronic pain referred for pain rehabilitation. Insight in case complexity of patients within subgroups on the basis of gender, pain duration, pain severity and pain location. These descriptions can be used as reference data for daily practice in the field of pain rehabilitation and can be used to evaluate, monitor and improve rehabilitation care in care settings nationwide as well as internationally.

1. Introduction

The Initiative on Methods, Measurements, and Pain Assessment in Clinical Trials (IMMPACT) published several articles on a core set of domains and measurement procedures for research within the field of chronic pain. Six core outcome domains were recommended: (1) pain, (2) physical functioning, (3) emotional functioning, (4) participant's rating of improvement and satisfaction, (5) symptoms and adverse events and (6) participation disposition (Turk et al., 2003). A core set with uniform measurements will facilitate a comprehensive comparison of effectiveness of different types of treatment strategies and/or pooling of data. If clinicians can compare the characteristics of their patient(s) with those presented in published research, this will facilitate more evidence informed decisions making regarding individual patient treatment strategies.

Because clinical practice may differ from controlled trials or other study designs, there is a great need for reference data collected within clinical practice to compare patient characteristics or treatment results. Likewise, patient characteristics also relate to the type of treatment offered or the setting of care. When curative medical solutions or interventions to reduce pain are not effective, patients are often referred for pain rehabilitation treatment. The key goal of pain rehabilitation is to develop adequate strategies to deal with pain and pain-related disabilities, and to resume daily functioning. So insight in patient characteristics and severity of complaints is of utmost importance for rehabilitation care because content, dosage and (cost) effectiveness of treatment seem to depend on case complexity (Scerri et al., 2006; van Middelkoop et al., 2011; Kamper et al., 2015; Waterschoot et al., 2016).

To measure patient characteristics and outcomes of pain rehabilitation treatment, the Taskforce Dataset Pain rehabilitation (TPD) of the Task group Pain Rehabilitation of the Dutch Association for Rehabilitation Physicians (WPN-VRA) developed the Dutch Dataset Pain Rehabilitation (DDPR). (Köke et al., 2007).

Between 2010 and 2013 this core set was implemented in 32 Dutch rehabilitation facilities. The goal of this article is to present baseline characteristics of patients referred to pain rehabilitation treatment in the Netherlands. The primary aim is to provide a description of sociodemographic variables (age, gender and work status), pain-related variables such as pain locations, pain severity and pain-related disability of patients with chronic nonspecific

musculoskeletal pain referred for pain rehabilitation treatment in the Netherlands. Providing comprehensive multidisciplinary treatment that is based on the severity or complexity of pain problems warrants insight in possible subgroups of patients. Therefore, descriptions of all variables for specific subgroups based on treatment facility (hospital or centre), gender, pain severity (mild, moderate and severe), pain locations and on pain duration are provided. These descriptions can be used as reference data for daily practice while referring to pain rehabilitation as well as to facilitate the selection of treatment strategies, implement new evidence-based treatments (based on generalizability of study results to population treated in the clinical practice) and to evaluate, monitor and improve rehabilitation care (inter)nationally. However, this needs international agreement on content and standardization of measurements tools.

2. Methods

2.1 Development of DDPR

The development process is briefly described to understand the content of the core set (for more detailed description, see Köke et al., 2007). The content of the DDPR was based on the IMMPACT set (Turk et al., 2003; Dworkin et al., 2005) and the ICF Core Sets low back pain (Cieza et al., 2004a) and chronic widespread pain (Cieza et al., 2004b) as well as a systematic review on factors predictive for positive or negative pain rehabilitation programme outcomes (van der Hulst et al., 2005). From the three aforementioned core sets, the outcome domains, specific relevant for clinical use within pain rehabilitation were selected. Next, valid, reliable and responsive measurements were selected for each outcome domain. These measurements had to be short and freely available in the Dutch language with proven sufficient validity, responsiveness and reliability. This resulted in the first version of the DDPR, which was presented to all rehabilitation physicians of the WPN-VRA. They were asked to provide feedback, which was used to redefine and extend the content of DDPR (Delphi method). This process was repeated four times until overall consensus (>90% agreement among participants) was reached. This resulted in the final DDPR as presented in this study. The DDPR consists of eight domains (Table 1), meaning that three domains were added to the five domains of the IMMPACT set; medical consumption, patient-specific goals, and activities/participation as these domains

are important targets of pain rehabilitation in the Netherlands.

Because societal costs of chronic pain are high, the domains medical consumption and activities/participation were added to the DDPR. Patient-specific goals were added based on the client centred care approach used in pain rehabilitation in the Netherlands. Because patients with chronic pain have very diverse personal, environmental and clinical characteristics, pain rehabilitation is tailored to the patient's needs. Hence, it is important to measure specifically whether this approach is successful.

In addition, because pain rehabilitation does not aim to cure chronic pain but to teach patients how to cope with pain and pain-related disability, less disability and better work participation are primary treatment goals. The DDPR consists of 97 questions/items; 42 for sociodemographic and pain-related data and the remaining 55 were items from the included questionnaires. In Table 1 the selected measurement instruments for each domain are presented.

The purpose of this article is to describe the characteristics of the referred patients for pain rehabilitation in the Netherlands. Because referral for pain rehabilitation is often regarded as a last resort, it was

hypothesized that these referred patients can be characterized as representing a heterogeneous group of patients with chronic pain. Therefore, description of the characteristics was also done for subgroups based on treatment facility (hospital or centre), gender, pain severity (mild, moderate and severe), pain locations and pain duration.

It also was hypothesized that patients referred to hospital departments had less complex pain problems (less disability and less psychosocial problems) than those referred to rehabilitation centres, that female patients had more complex pain problems than male (Greenspan et al., 2007) and, finally, that higher pain severity, longer duration and more pain locations resulted in higher case complexity (higher disability scores and higher scores on emotional and cognitive functioning).

2.2 Data collection

Data were collected during an implementation project of the DDPR. In total, 32 specialized pain rehabilitation facilities (18 hospitals and 14 rehabilitation centres) in the Netherlands participated in this implementation study. All referred patients completed the measures at first consultation with the rehabilitation physician. In the Netherlands, the content of pain rehabilitation programmes is mainly based on physical reactivation combined with cognitive-behavioural treatment, to teach patients to cope with their pain and pain-related disability. In general, a pain rehabilitation team, under supervision of the rehabilitation physician, consists of a physical therapist, an occupational therapist and a psychologist and/or a social worker. The duration of a pain rehabilitation programme in the Netherlands is on average 12 weeks (range 4–20 weeks) (Goossens et al., 2002). A general physician or a medical specialist can refer patients. In the Netherlands, patients are mostly referred to a pain rehabilitation programme as a 'last resort'; when all other pain-reducing treatment options have failed. The Dutch health care insurance companies provide full payment for pain rehabilitation.

Two existing and in the Netherlands available digital systems ('Pijndossier' and 'Klinilyzer') were used for data collection. For 'Pijndossier', patients were sent a personal code for the secured web application by email, so patients could fill out the questionnaires at home. For Klinilyzer, DDPR was filled out on paper and afterwards members of the team entered the data in Klinilyzer to calculate the scores, which then could be viewed by the caregivers.

Table 1 Domains and instruments of the Dutch Dataset Pain Rehabilitation.

Domains	Measurement instruments
Pain and fatigue	11-point numeric rating scale NRS
Physical functioning	Subscale physical functioning Short-Form, (PF/SF-36) Subscale role limitations physical Short-Form; (RP/SF-36) Subscale interference Multidimensional Pain Inventory (MPI)
Emotional functioning	Subscale mental health Short-Form, (MH/SF-36) Subscale vitality Short-Form (VI/SF-36) Pain Catastrophizing Scale (PCS)
Activities and participation	Pain Disability Index (PDI)
Medical consumption	Open questions about doctor's/other health care practitioner's visits and medication use
Patients rating of improvement and satisfaction ^a	Global Perceived Effect (GPE)
Patient-specific goals ^a	Canadian Occupational Performance Measurement (COPM) or Patient-Specific Functional Status (PSFS)
Symptoms and adverse events ^a	Open questions

^aIn this article only baseline data are presented, therefore data on the last three domains are not presented.

2.3 Content of DDPR

2.3.1 Patient characteristics

To describe the patient population, sociodemographic data such as gender, age, marital status, work, education and referring physician were collected. Also general pain-related data such as pain site, pain onset, pain duration and patient's beliefs about the cause of the pain were collected (in total 42 questions).

2.3.2 Pain and fatigue

The severity of pain is measured with a 0–10 numerical rating scale (NRS pain) of average pain over the past 7 days (0 = no pain at all, 10 = worst pain imaginable). The severity of fatigue over the past 7 days is measured using a self-administered 0–10 numerical rating scale (NRS fatigue) (0 = no fatigue, 10 = completely exhausted). Numeric rating scales are valid and reliable measurement tools, but this needs to be established for all patient groups (Jensen et al., 1986; Hawker et al., 2011).

2.3.3 Physical functioning

For physical functioning three measurement tools are used. The subscale pain interference (9 items) of the Multidimensional Pain Inventory (MPI) (Kerns et al., 1985) is used to measure interference of pain on daily activities. The interference is scored on a 7-point Likert scale (0–6), with higher values representing higher levels of pain interference on daily functioning. To measure the activity limitations, the Physical Functioning Scale (PF, 10 items) and Role Physical (RP, 4 items) of the 36-Item Short Form Health Survey (SF-36) are used. Scores range from 0 to 100 and higher scores indicate better physical functioning (Aaronson et al., 1998). The Dutch MPI and all subscales of the Dutch SF36 are valid and reliable measurement tools (Aaronson et al., 1998; Lousberg et al., 1999).

2.3.4 Emotional and mental functioning

For emotional and mental functioning three constructs are measured: pain catastrophizing, vitality and mental health. The Pain Catastrophizing Scale (PCS, 13 items) (Sullivan et al., 1995) measures pain-related catastrophizing and worrying. The items are rated on a 5-point scale (0 = not at all, 4 = always). A higher score means that a patient has more catastrophizing thoughts about pain. The Dutch PCS is sufficiently valid and reliable (van

Damme 2000). Vitality and mental health are measured with the subscale vitality (VT, 4 items) and mental health (MH, 5 items) of the 36-Item Short-Form Health Survey (SF-36). Scores range from 0 to 100 and higher scores indicate better emotional functioning. The validity and reliability are adequate (Aaronson et al., 1998).

2.4 Activities and participation

The Pain Disability Index (PDI, 7 items) (Tait et al., 1987) measures the self-reported disability in different domains such as work, leisure time, activities of daily life and sports on an 11-item numeric rating scale in which 0 means no disability and 10 maximum disability. The total score ranges from 0 to 70. Higher scores indicate more restrictions in activities and participation. The PDI has two subscales: (1) voluntary activities (PDI items 1–5; family/home responsibilities; recreation; social activity; occupation and sexual behaviour) and (2) obligatory activities (items 6 and 7; self-care and life support activity). The Dutch PDI is a valid and reliable measurement tool (Soer et al., 2012, 2013).

2.5 Analyses

Only data from the first assessment, prior to the first consultation, which were used for analyses. For the domains 'Patients rating of improvement and satisfaction', 'Patient Specific Goals' and 'Symptoms and adverse events' data were collected at the end of treatment and therefore these data are not presented in this article describing the characteristics of referred patients.

The sociodemographic and pain-related general variables were described in means or percentages, only for the total group. For the scores of the questionnaires, means and standard deviation were calculated for the total group and specific for treatment facility (hospital or centre), gender (m/f) and subgroups based on pain severity; mild (NRS 1–4), moderate (NRS 5–6) and severe (NRS 7–10) (Jensen et al., 2001), extend of pain locations (multisite pain: 1 pain location, 2–5 pain locations and more than 5 pain locations) and pain duration (1, 1–2, 2–5 and 5 years). Comparison between subgroups was based on ANOVA with *post hoc* tests Bonferroni (to control for type I error) and Hochberg's GT2 test (to control for different sample sizes). Statistical significance was set at $p < 0.05$. Results were presented as statistically significant if both *post hoc* tests had a $p < 0.05$.

3. Results

From February 2010 to October 2013, a total of 8200 adult chronic pain patients were referred for pain rehabilitation. All referred patients completed the measures at first consultation with the rehabilitation physician. Although all patients were asked to fill out the complete DDPR, several data were missing, ranging from 1559 for pain severity to 3862 for PCS. No systematic bias or pattern regarding gender, age, educational level or work status was found for the missing data. Therefore, we decided to present all available data (mean/SD) in this article. More detailed description of the data mean (SD) and median (percentiles) available upon request by first author.

First, the general patient characteristics are presented, and secondly the scores of the specific measurement tools in the domains of the DDPR are reported.

3.1 General patient characteristics

No statistically significant differences were found on either general patient characteristics or scores on measurement tools between hospitals and rehabilitation centres. Therefore, only data from the total group are presented (detailed data available upon request by first author).

Sociodemographic characteristics of the patients are presented in Table 2. Pain-related characteristics and referral sources are presented in Table 3. The majority of the patients were woman (71%) and mainly Dutch citizen (87%). Although patients between 18 and 90 years of age were referred, most patients were between 30 and 60 years old (74%), with an average age of 43 years. Of all patients, 16% had no partner/spouse. Patients were referred to pain rehabilitation programme by all types of medical specialists, but the majority by a general practitioner (Table 3). Also, the rheumatologists and rehabilitation physicians referred a high percentage of patients. The latter can be explained by the fact that not all rehabilitation facilities offer specialized pain rehabilitation programmes in the Netherlands. Patients reported that their pain onset was mainly gradual without a specific cause or occasion. Although most frequent pain complaints were located in the lower back, shoulder and neck, most patients had more than one body part that was painful. Furthermore, the majority of the patients (61%) had pain complaints for more than 2 years.

Medical consumption prior to referral is presented in Table 4. A variety of health care practitioners were visited during the year before referral. Almost every patient had consulted a general practitioner in

Table 2 Sociodemographic characteristics of the study population.

	Percentage or mean (SD)
Female (%), (n = 6517)	71
Age in years (mean/SD), (n = 6561)	43.4 (12.6)
Age groups (%), (n = 6561)	
18–20	2.9
21–30	15.3
31–40	21.5
41–50	29.8
51–60	22.4
61–70	6.8
71–90	1.3
Birthplace (%), (n = 7797)	
The Netherlands	87
Other countries	13
Marital status (%), (n = 8097)	
Single	39
Married	61
Children yes (%), (n = 8038)	61
1 Child	22
2 Children	50
3 Children	19
≥4 Children	9
Education, (n = 7687)	
<10 years	13
10–12 years	70
>12 years	17
Current work status (%), (n = 6821)	
Paid job	48
Unpaid job	9
Unemployed	17
Retired	4
Student	4
Household	18
Using hard or soft drugs in the past (%), (n = 8045)	3
Using hard or soft drugs presently (%)	3
Using >8 units alcohol per week (%), (n = 8058)	13

	Male, (n = 1067) %	Female, (n = 2484) %
Body mass index (BMI)		
BMI < 18.5	1	2
BMI 18.5–24.9	34	42
BMI 25–29.9	45	32
BMI ≥ 30	20	24

the year before referral. Thereafter, the physical therapist was most frequently consulted (56%), followed by the neurologist (34%), rheumatologist (20%) and the orthopaedic surgeon (19%). Most patients used pain medication, often on a daily basis.

3.2 Scores of the domains of the Dutch Dataset Pain Rehabilitation (DDPR)

The scores for pain, fatigue, PDI, SF-36 subscales, PCS and MPI-interference daily life are presented for

Table 3 Pain-related characteristics of the study population.

	Percentages
Pain site (%), (n = 4596)	
Head & face	38
Cervical region	45
Shoulders	46
Upper limbs	34
Hand/fingers	32
Chest & abdomen	13
Lower back, lower spine, sacrum	58
Lower limbs: hip and thigh	34
Lower limbs: knee	39
Lower limbs: foot	29
Other	14
Local/multisite pain (%), (n = 4596)	
1 Pain location	15
2–5 Pain locations	39
>5 Pain locations	46
Pain onset (%), (n = 8193)	
Gradual, without a known cause	57
Sudden after trauma	26
Sudden without a cause	17
Self-reported cause of pain (%), (n = 5251) ^a	
Physical injury	28
Overload at work	19
Overload at home	11
Accident	19
Surgery	9
Illness	11
Unknown	27
Pain duration (in months), (n = 7528)	
6–12	21
13–24	18
25–60	23
>61	38
Referring physician, (n = 8200)	
General practitioner	38
Rheumatologist	15
Rehabilitation Physician	14
Orthopaedic surgeon	10
Neurologist	10
Anaesthesiologist	5
Psychiatrist	1
Other	7

^aMore than one answer was allowed.

the total group and by gender (Table 5), by pain intensity (Table 6), by multisite pain (Table 7) and by age groups (Table 8). Data were also analysed based on subgrouping by duration of pain. However, differences between subgroups on duration of pain were small and nonsignificant and therefore not presented (available upon request by first author).

Differences between men and women were generally small. Women had statistically significant lower physical functioning, more role limitations physical

Table 4 Medical consumption in year before referral.

Health care practitioner visits past year, (n = 7795)	Percentages
0×	1.1
1–2×	13.0
3–5×	25.0
6–10×	26.0
11–20×	19.4
>20×	15.5
Medication, (n = 7991)	
Using pain medication	59
Daily use of pain medication	51
Other medication, (n = 7643)	43

and lower vitality scores. Men had a statistically significant higher score on catastrophizing.

On average patients reported high levels of pain and fatigue scores during the past week (Table 6). Most patients (61%) reported severe pain and only a minority of 6% had mild pain. The subgroup of patients with severe pain (7–10) reported the worse scores on all measurements. All differences between the scores on the different measurements in the

Table 5 Overview of total scores for all patients and for men and women.

	All patients, mean (SD)/n	Males, mean (SD)/n	Females, mean (SD)/n
Pain (NRS) (0–10)	6.7 (1.8)/6641	6.5 (1.9)/1433	6.6 (1.8)/3548
Fatigue (NRS 0–10)	7.0 (2.2)/6209	6.6 (2.3)/1303	7.1 (2.1)/3238
PDI (0–70)	38.9 (13.3)/4867	38.1 (14.1)/1195	38.7 (13)/3002
PDI voluntary activities	32.3 (9.9)/4876	30.6 (10.6)/1199	31.3 (9.6)/2999
PDI obligatory activities	7.7 (4.9)/5003	7.6 (4.9)/1207	7.6 (4.8)/3106
SF-36 PF (0–100)	43.5 (22.1)/5181	44.5 (22.6)/1281	42.9 (21.8)/3274 ^a
SF-36 RP (0–100)	11.1 (24)/5356	12.5 (25.4)/1304	10.7 (23.6)/3420 ^a
SF-36 MH (0–100)	61.6 (18.7)/5306	61.2 (18.8)/1299	62.2 (18.2)/3375
SF-36 VT (0–100)	41.1 (18.4)/5255	43.6 (19.1)/1280	40.5 (18)/3344 ^b
PCS (0–52)	21.6 (10.8)/4338	23.3 (11.1)/1155 ^b	21.1 (10.5)/2831
MPI-INT (0–6)	4.0 (1.2)/4655	4.0 (1.3)/1181	4.0 (1.2)/2884

NRS, numeric rating scale; PDI, pain disability index; SF-36, Short Form -36; PF, physical functioning; RP, role limitations physical; MH, mental health; VI, vitality; PCS, pain catastrophizing scale; MPI-INT, Multidimensional pain inventory Interference scale.

^ap < 0.05.^bp ≤ 0.000.

Table 6 Overview of subgroups according to pain severity.

	Patients with pain score 1–4, mean (SD)/n	Patients with pain score 5–6, mean (SD)/n	Patients with pain score 7–10, mean (SD)/n
Pain average past week (0–10)	3.1 (1.1)/795 ^a	5.6 (0.5)/1761 ^b	7.8 (0.9)/4085 ^c
Fatigue average past week (0–10)	5.4 (2.5)/747 ^a	6.5 (2)/1631 ^b	7.5 (1.9)/3730 ^c
PDI (0–70)	27.6 (13)/589 ^a	34.7 (11.5)/1291 ^b	43.2 (12.2)/2759 ^c
PDI voluntary activities	23.2 (10.5)/590 ^a	28.5 (8.8)/1292 ^b	34.3 (8.9)/2762 ^c
PDI obligatory activities	4.5 (3.9)/603 ^a	6.3 (4.4)/1325 ^b	9.0 (4.8)/2844 ^c
SF-36 PF (0–100)	58.4 (21)/562 ^a	49.8 (20.1)/1246 ^b	38.9 (21.3)/2707 ^c
SF-36 RP (0–100)	50.5 (30.8)/574 ^a	13.3 (25.7)/1297 ^b	8.3 (20.8)/2791 ^c
SF-36 MH (0–100)	68.1 (16.1)/570 ^a	65 (16.9)/1295 ^b	58.7 (19.1)/2762 ^c
SF-36 VT (0–100)	49.6 (18.1)/572 ^a	43.8 (18)/1286 ^b	38.5 (19.1)/2762 ^c
PCS (0–52)	15.6 (9)/536 ^a	18.6 (9.1)/1213 ^b	24.5 (11)/2349 ^c
MPI-INT (0–6)	3.2 (1.3)/580 ^a	3.7 (1.1)/1296 ^b	4.3 (1.1)/2584 ^c

NRS, numeric rating scale; PDI, pain disability index; SF-36, Short Form -36; PF, physical functioning; RP, role limitations physical; MH, mental health; VI, vitality; PCS, pain catastrophizing scale; MPI-INT, Multidimensional pain inventory interference scale.

^{a,b,c} $p = 0.000$ between group 1–4 versus group 5–6 and group 7–10 NRS, and between 5–6 and 1–4 versus 7–10, and between 7–10 versus 1–4 and 5–6.

Table 7 Overview of subgroups according to pain (multi)locations (multisite pain).

	Patients with 1 pain location, mean (SD)/n	Patients with 2–5 pain locations, mean (SD)/n	Patients with > 5 pain locations, mean (SD)/n
Pain (NRS 0–10)	6.4 (2.1)/588 ^a	6.7 (1.8)/1856 ^b	7 (1.7)/1363 ^c
Fatigue (NRS 0–10)	6 (2.5)/582 ^a	6.7 (2.3)/1816 ^b	7.5 (1.9)/1310 ^c
PDI (0–70)	35.9 (14.5)/383	37.4 (13.9)/1274 ^b	40.9 (12.6)/1118 ^c
PDI obligatory activities	29.4 (11.1)/381	30.3 (10.4)/1279 ^b	32.7 (9.2)/1120 ^c
PDI voluntary activities	6.7 (4.9)/399	7.2 (5.0)/1320 ^b	8.5 (4.7)/1153 ^c
SF-36 PF (0–100)	48 (23.4)/391 ^a	48 (22.8)/1257 ^b	40.9 (20.7)/1099 ^c
SF-36 RP (0–100)	17.4 (30.2)/397	14.1 (26.4)/1289 ^b	8.6 (20.3)/1137 ^c
SF-36 MH (0–100)	64.2 (17.2)/393	63.4 (17.8)/1283 ^b	60.3 (18)/1123 ^c
SF-36 VT (0–100)	48.5 (17.5)/389 ^a	45.7 (17.5)/1273 ^b	37.7 (17.1)/1112 ^c
PCS (0–52)	18.8 (10.3)/215 ^a	21.7 (10.5)/959	22.3 (10.9)/879
MPI-INT (0–6)	3.5 (1.3)/243 ^a	3.9 (1.2)/1017 ^b	4.1 (1.1)/896 ^c

NRS, numeric rating scale; PDI, pain disability index; SF-36, Short Form -36; PF, physical functioning; RP, role limitations physical; MH, mental health; VI, vitality; PCS, pain catastrophizing scale; MPI-INT, Multidimensional pain inventory interference scale.

^a $p \leq 0.05$ between group 1 loc. versus group 2–5 loc.

^b $p \leq 0.000$ between group 2–5 loc. versus group >5 loc.

^c $p \leq 0.000$ between group >5 and group 1 and group 2–5 loc.

subgroups of pain intensity were statistically significant, even after *post hoc* corrections ($p < 0.000$).

Patients with multiple pain locations (>5) had worse scores on pain severity, fatigue, disability (PDI), physical (SF36-PF and RP), emotional functioning (SF36 MH and VI), catastrophizing (PCS) and pain interference (MPI) (Table 7) compared to the group with 1 location, and 2–5 locations.

Patients with 2–5 pain locations had significantly worse scores than patients with 1 pain location on pain severity, fatigue, vitality (SF36 VI), catastrophizing (PCS) and pain interference (MPI).

Patients with 2–5 locations had better scores on pain, fatigue, disability (PDI), physical (SF36-PF and RP), emotional functioning (SF36 MH and VI) and

pain interference (MPI) compared to group with >5 pain locations.

Patients with a pain duration > 5 years had statistically significant worse scores on fatigue, physical functioning (SF36-PF) and vitality (SF36-VI) compared with all other subgroups on pain duration. Also patients with a pain duration of >5 years had significantly higher pain intensity than patients with a pain duration of 1 year, and more limitations in role physical functioning (SF36 RP) compared to the group with a 1 year and the group with a 1–2 years pain duration (Table 8).

Also patients with a pain duration >5 years had statistically significant higher PDI scores compared to the patients reporting a pain duration of 2–5 years.

Table 8 Overview of subgroups according to pain duration.

	Patients with pain duration 1 year, N = 1349, N = mean, (SD)/n	Patients with pain duration 1–2 years, N = 1056, mean (SD)/n	Patients with pain duration 2–5 years, N = 1335, mean (SD)/n	Patients with pain duration > 5 years, N = 2212, mean (SD)/n
Pain (NRS 0–10)	6.5 (1.9)/1349	6.6 (1.8)/1056	6.6 (1.8)/1335	6.7 (1.8)/2212
Fatigue (NRS 0–10)	6.8 (2.3)/1312	6.9 (2.2)/1016	6.9 (2.2)/1281	7.2 (2.1)/2104
PDI (0–70)	39.3 (13.9)/969	39.3 (13.4)/861	37.3 (13.7)/1037	38.6 (13)/1657
PDI obligatory activities	31.7 (10.4)/971	31.6 (9.9)/860	30.1 (10.2)/1037	31.1 (9.6)/1666
PDI voluntary activities	7.8 (5.0)/994	7.8 (5.0)/886	7.3 (4.8)/1058	7.6 (4.8)/1711
SF36 PF (0–100)	45.2 (22.1)/1022	43.8 (22.1)/912	46.1 (22.2)/1110	41.5 (21.9)/1805
SF36 RP (0–100)	8.3 (21.0)/1065	9.4 (21.7)/929	13.4 (26.7)/1148	12.9 (25.6)/1874
SF36 MH (0–100)	61.3 (18.7)/1052	61.5 (19)/928	62.8 (18.2)/1134	61.5 (18.6)/1859
SF36 VT (0–100)	42.2 (17.7)/1038	42.3 (18.7)/919	42.8 (18.2)/1123	39.8 (18.4)/1843
PCS (0–52)	20.7 (10.4)/775	22.4 (10.6)/679	22.2 (10.7)/846	21.6 (11)/1379
MPI –INT (0–6)	4 (1.2)/861	4 (1.2)/735	3.9 (1.2)/928	4 (1.2)/1512

NRS, numeric rating scale; PDI, pain disability index; SF-36, Short Form -36; PF, physical functioning; RP, role limitations physical; MH, mental health; VI, vitality; PCS, pain catastrophizing scale; MPI-INT, Multidimensional pain inventory interference scale.

Patients with pain duration of 2–5 years had higher PDI scores compared to the 1 year pain duration group, and more role limitations compared to the 1 and 1–2 year pain duration group. No differences regarding pain severity, fatigue, physical functioning, mental health and vitality were found between the groups of 1, 1–2 and 2–5 years pain duration. General clinical features differed slightly between these groups but were clinically irrelevant (Table 8).

4. Discussion

The DDPR gives insight in sociodemographic characteristics, severity of symptoms and complaints of patients with chronic pain referred for pain rehabilitation treatment. Surprisingly, no differences were found between patients referred to hospitals and rehabilitation centres. As the majority of patients, in both facilities, had pain complaints longer than 1 year this might explain this finding.

In general, the sociodemographic characteristics and medical consumption (medication use/doctor visits) are comparable to descriptions in general populations (Breivik et al., 2006; Bekkering et al., 2011) and/or patients of a tertiary Pain Management and Research Centre in Australia (Nicholas et al., 2008). The average scores on pain, pain duration, physical and emotional functioning for the total group are similar to a sample of patients from Australia (Nicholas et al., 2008). Scores in domain participation (PDI) resemble those of a workers' compensation sample in Canada, and a Multidisciplinary Spine Centre in the Netherlands (Soer et al., 2015). Scores for physical and emotional functioning (SF36) were similar to data of SF-36 found in a study on quality of life in the

Netherlands in patients with musculoskeletal diseases (Picavet and Hoeymans, 2004). Although the patients referred for rehabilitation had, in our opinion, highly complex chronic pain problems, definite conclusions cannot be drawn from the data, as no other data systematically gathered by a clinical core set in other care settings are available in the current literature.

Comprehensive descriptions of characteristics of patient samples are important to enhance knowledge transfer (Thorn et al., 2007). This project provides a detailed insight in patient characteristics of patients referred for pain rehabilitation treatment.

Also these data are important because a lack of reference data limits the interpretation of scores in individual cases, which is useful for the planning of a proper treatment (Nicholas et al., 2008). The results of this study seem to underpin the importance of a biopsychosocial perspective in the care of patients with chronic pain (Gatchel et al., 2007, 2014) as scores in domains of physical and emotional functioning and disability were worse. Pain rehabilitation treatment is an effective treatment modality (Kamper et al., 2015). However, effect sizes are small to moderate and different types of pain rehabilitation treatment seem equally effective (Morley et al., 1999; Eccleston et al., 2009; Kamper et al., 2015; van Tulder et al., 2000). Heterogeneity of the patient populations might explain these small-to-moderate effects (West et al., 2010; van Middelkoop et al., 2011). Collecting data in a standardized way might be helpful to answer the question 'What works for whom', by identifying baseline characteristics and subgroups that predict treatment effectiveness. A tailored treatment, based on case complexity, might improve treatment effectiveness (Scerri et al., 2006).

Pain rehabilitation treatment is often regarded as a last resort treatment option, often after a long period of (unsuccessful) pain-reducing treatments. The results of this study, in which approximately 80% of the referred group had pain lasting longer than 1 year and for 38% even longer than 5 years, show that late referral for pain rehabilitation treatment is indeed common. This is in agreement with data from the European study of Breivik et al. (2006), which showed that only a small proportion of patients with chronic pain were finally referred to specialized pain facilities and that many patients (40%) were not satisfied with the effect of prior pain-controlling treatments.

Although pain rehabilitation is not effective in curing the pain, late referral for pain rehabilitation treatment might have several disadvantages for patients (more and severe complaints and impairments) and society (higher direct and indirect costs by work absence and more medical costs) (Kronborg et al., 2009). The longer the pain complaints persist the higher the risk for developing more generalized or wide spread pain and higher case complexity. Our data showed indeed that patients with longer pain duration had more severe complaints on pain, fatigue, physical functioning and vitality and partly for catastrophizing and role limitations physical.

Spreading of pain from local or regional pain to widespread or multisite pain occurs in a large proportion of the population (Larsson et al., 2012). In total, 85% of the patients suffered from pain in several parts of the body. Spreading of pain might be explained by abnormal central pain processing (central sensitization), rather from injury to anatomic body structures (Meeus and Nijs, 2007; Woolf, 2007, 2011; Roussel et al., 2013).

Patients with more severe pain or multisite pain reported more disability and emotional problems, which are factors that can contribute to abnormal pain processing resulting in central sensitization (Brosschot, 2002; Woolf, 2011). Also, central sensitization can occur relatively rapidly (within days to weeks) and once established it is difficult to treat (Latremoliere and Woolf, 2009). This might explain why duration of pain did not show large differences in severity of complaints in this study as most patients had complaints of 6 months and longer.

One can imagine that patients with severe pain and other complaints may be very difficult to treat based on case complexity and previously failed treatments (van Wilgen et al., 2009). An early multidisciplinary approach seems appropriate as negative physical and psychosocial factors or consequences of

pain, which contribute to hyper pain sensitivity, can be treated or prevented. Earlier referral for comprehensive multidisciplinary treatment might improve cost effectiveness because the case complexity is probably lower (Kronborg et al., 2009).

This study also showed that patients frequently visit health care professionals before their referral for pain rehabilitation treatment. Chronic pain in general and higher pain-related disability are associated with greater use of health care services (Blyth et al., 2004; Mann et al., 2016), this might explain high medical consumption in our study sample. Although no data for medical consumption for the total period of pain duration were collected, the medical consumption in the year prior to referral was high, even in patients with long pain duration (>5 years). So one can assume that total medical consumption is very high in this group of patients, resulting in high medical costs. As pain rehabilitation treatment has a positive impact on medical consumption, (Turk et al., 2006) and return to work/disability (Linton et al., 2005; Norrefalk et al., 2008), again this is an important reason for earlier referral for pain rehabilitation treatment.

5. Limitations of the DDPR

Due to the expected heterogeneity of the patient group and assumed differences in type of referred patients to all the centres, more generic subscales of the SF36 were chosen, instead of more specific disease-related questionnaires. However, validity, reliability and responsiveness of the SF36 are appropriate in several chronic pain conditions (Taylor et al., 1999; Lingard et al., 2001; Davidson and Keating, 2002; Walsh et al., 2003; Stewart et al., 2007; Veehof et al., 2008). The final DDPR also contained more instruments on the domain of physical functioning (generic and specific) compared to emotional functioning. The reason for this choice was that physical functioning was seen as the important outcome specific for rehabilitation. Combining generic and disease-specific measures is useful for broader assessment (Taylor et al., 1999). Also it was difficult to achieve consensus on more specific questionnaires in domain emotional functioning, such as mood questionnaires. To limit the burden of filling out too many questions, more generic measures were chosen. However, this limits specific information about mood disturbances.

Furthermore, data collection was not optimal or complete in all settings. In some settings, the DDPR was implemented only partly. This explains the large

number of missing data on PCS and MPI, as they were added later to the existing data set. The main reason for poor data collection was the underestimation of the amount of time and/or necessary resources (computers/staff) to realize this within the treatment facilities. In most facilities the implementation was allocated to a secretary or a therapist of the team, without any specific knowledge of data collection or resources to manage it properly. Data collection appeared not to be the core business of treatment facilities. It is a separate task or function that needs to be structurally embedded in the organization. This resulted in unequal numbers of scores of the different measurement tools from the start. Also patients did not fill out all questions accordingly. Maybe for some patients it was too time consuming or the content of the questions was too private (such as questions about sex life) or patients had difficulties in handling the computer program for data collection.

In future, it is necessary that treatment facilities invest in developing an adequate infrastructure for data collection, monitoring and management and proper training of involved people.

The large number of missing data for several measurement tools could have biased the results. Missing data were mostly due to differences at the start of data collection in this project. A comparison of missing data per subgroup presented in the Result section did not show significantly different percentages of missing data between subgroups (gender, duration, pain severity). In our opinion the presented data give a good overview of the characteristics of chronic pain patients referred for rehabilitation programmes (in the Netherlands).

It is now important to collect further data of baseline characteristics, process measures and results of pain rehabilitation treatment. Such data might help to identify (subgroups of) patients, who can be successfully treated by pain rehabilitation programmes. This study showed that patients with musculoskeletal chronic pain referred for pain rehabilitation treatment have a long history of pain and high case complexity. Earlier referral for pain rehabilitation treatment (or other forms of comprehensive multidisciplinary treatment) can be useful to prevent severe complaints and improve daily functioning.

Author contributions

All authors were involved in data collection and data analysis during the project. All authors discussed and commented on several versions of the manuscript resulting in this final manuscript.

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