Bodily changes and sensory sensitivity in complex regional pain syndrome and fibromyalgia

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Number of pages: 24

Number of figures: 1

Number of tables: 4

Parts of the results were presented on a poster at the 7th scientific meeting of the Federation of the European Societies of Neuropsychology. It was not published in the form of an article before.

Keywords: complex regional pain syndrome; fibromyalgia; somatic sensations; sensory sensitivity; bodily changes

Abstract

Complex regional pain syndrome (CRPS) and fibromyalgia are chronic pain conditions of unexplained origins. In addition to symptoms in the diagnostic criteria, patients can report changes to vision and other sensations or bodily functions. It is unclear whether these are greater than would be expected due to normal ageing, living with chronic pain generally, or common co-morbidities of chronic pain such as depression or anxiety. We administered an on-line survey evaluating the frequencies and types of self-reported somatic symptoms, bodily changes, and sensory sensitivity in respondents with CRPS (*n*=390), fibromyalgia (*n*=425), and both CRPS and fibromyalgia ('CRPS+fibromyalgia'; *n*=88) compared to respondents with other chronic pain conditions (*n*=331) and pain-free controls (*n*=441). The survey assessed somatic symptoms (Patient Health Questionnaire-15), bodily changes, pain/discomfort/distress triggers, and pain intensifiers. We conducted ANCOVA's with age, sex, the Patient Health Questionnaire-9 (measuring depression), the Generalized Anxiety Disorder-7, pain duration in years, hours of pain per day, and number of pain-related medical diagnoses as covariates. After controlling for covariates, respondents with CRPS and/or fibromyalgia reported more somatic symptoms, changes in movement and biological responses, pain/discomfort/distress triggers, and pain intensifiers than pain(-free) control groups. Fibromyalgia specifically related to changes in vision and hearing; urinary/intestinal function; and drinking and eating. CRPS changes related to changes in hair, skin, and nails; and infection and healing. The CRPS+fibromyalgia group presented with features of both disorders with minimal additional stressors or symptoms over and above these. Our findings suggest CRPS and fibromyalgia share underlying pathophysiologies, although specific mechanisms might be different.

1. Introduction

Complex regional pain syndrome (CRPS) and fibromyalgia are musculoskeletal pain conditions with distinct clinical phenotypes, but many overlapping features [35,36,38]. CRPS involves regional pain [4,52], whereas fibromyalgia involves widespread pain [18,19,56]. Both syndromes are associated with functional and structural changes in the central nervous system (CNS) [21,27,35,60]. People with CRPS and fibromyalgia show hyperalgesia (increased responses to painful stimuli) and allodynia (pain from a normally non-painful stimulation) [35,38], which is absent or less severe in other pain conditions such as arthritis [43], and has been attributed to central sensitisation [1,25,60]. Furthermore, there is some recent indication that CRPS and fibromyalgia are associated with condition-specific circulating, pain-sensitising autoantibodies [2,9,10,15].

In addition to heightened sensitivity to somatosensory stimuli, it is proposed that in both CRPS and fibromyalgia sensory input across many systems is amplified by the CNS, leading to enhanced sensory sensitivity for non-somatic stimuli [13,29]. CRPS and fibromyalgia are associated with greater sensitivity for visual, auditory, and olfactory stimuli compared to other pain disorders such as rheumatoid arthritis [8,14,16,29,46,55]. Compared to pain-free controls or people with other pain conditions, there is some evidence that people with CRPS show more vasomotor symptoms (e.g., differences in colour, temperature), trophic signs (e.g., changes in hair and nail growth), motor signs (e.g., restricted range of movement, tremor) [28,38]; and people with fibromyalgia report more fatigue, headache, nausea, hair loss [57], sensitivity for weather [41], and food intolerance [13]. Additionally, preliminary data shows that both people with CRPS and those with fibromyalgia report more bowel and bladder symptoms, and dryness of the mouth and eyes [38,59].

People with CRPS and fibromyalgia report a range of sensory and bodily symptoms, many of which are not part of the diagnostic criteria for those disorders. It is unknown whether

the nature of such additional sensory and bodily symptoms differs between CRPS, fibromyalgia and other chronic pain conditions. This is because these symptoms have neither been compared using uniform assessment criteria [38], nor been considered in the context of normal ageing, and common comorbidities of chronic pain such as depression and anxiety [42].

The primary aim of this study was to systematically determine self-reported bodily changes and sensory sensitivity associated with CRPS and fibromyalgia. We selected these conditions as CRPS and fibromyalgia are both associated with disproportionately high service use and disability, have a poorly understood aetiology, are thought to involve central sensitisation, and people with these conditions seem to report unusual bodily changes and sensations more than people with other conditions. We were interested in whether having CRPS or fibromyalgia is associated with distinct profiles of bodily changes and sensory sensitivities over and above what could be expected due to anxiety, depression, living with chronic pain generally, and normal ageing. The secondary aim was to determine if having both CRPS and fibromyalgia, compared to having only one of these conditions, is associated with more severe clinical and pain-related characteristics (e.g., pain intensity, number of hours of pain, anxiety, depression), and/or more sensory sensitivity and bodily changes.

2. Methods

2.1 Survey

2.1.1. Survey distribution and demographics

We created an on-line survey using Qualtrics survey software [44] and collected data between July and December 2018. We distributed the online link to this survey among people with CRPS and pain-free controls who had previously taken part in other research in our lab. We specifically targeted people with CRPS and CRPS charities to make sure the group would be large enough to analyse. Additionally, we distributed the survey link amongst the Community

Participant Panel of the Psychology Department of the University of Bath, through patient newsletters and social media groups for a number of pain conditions, via our own social media, and to our friends and relatives. Given the relative rarity of CRPS, to attain a large sample we distributed the survey internationally. As we did not have sufficient resources to translate the survey, we stipulated that people should only respond if they felt comfortable reading and answering questions in English. We also stipulated that respondents should be aged 16 years or older. Information about the study was provided at the start of the survey alongside questions pertaining to informed consent.

The survey took about 20 to 40 minutes to complete. If respondents closed the survey, the answers provided to that point were saved. Respondents had the opportunity to enter a prize draw for one of four £50 Amazon.co.uk vouchers (or a local equivalent). We obtained information about the location of respondents at the moment of filling in the survey using IP addresses and Qualtrics location data where possible. We asked for respondents' age and gender. The research was approved by the committee on research ethics at the University of Bath (number 18-169), in accordance with the Declaration of the World Medical Association (www.wma.net). We uploaded a preregistration at the Open Science Framework [31]. See S1 for all survey questions.

2.1.2. Pain characteristics

We asked whether respondents had experienced pain on most days for 3 months or more. If this question was answered with 'no', the survey directed the respondent to the next section. If this question was answered with 'yes', the survey directed the respondent to additional questions about their pain. Further questions about pain asked how long respondents had been experiencing pain (in years), the average hours of pain per day, whether they had received a medical diagnosis for their pain condition, what this diagnosis was, and who they had received

their diagnosis from. We predefined 15 pain-related medical diagnoses; including CRPS (we did not dissociate between CRPS I and CRPS II, as many patients do not know which type they have) and fibromyalgia (S1). An 'other' option was included with a free-text box for respondents to specify additional diagnoses; multiple items were counted as separate diagnoses. We categorized the diagnoses in the 'other' box based on the coding system for medical research categorisation (Supplementary Table 1), outlined by UK Clinical Research Collaboration (https://hrcsonline.net/health-categories/). Respondents were also asked what event or injury triggered the onset of their pain condition. We predefined seven events/injuries (S1) and included an 'other' option with a free-text box. Using a selection of ten predefined body parts and a free-text 'other' box (S1), respondents were asked to indicate where in their body they experienced pain over the past week. We measured pain intensity using the Numeric Pain Rating scale [26,47]. Respondents were asked to select a number on a sliding scale ranging from 0 ('no pain') to 10 ('worst pain imaginable') that best reflected the average level of their pain over the last week for each body part that they experienced pain in, and in their body overall.

2.1.3. Depression and anxiety

The Patient Health Questionnaire-9 (PHQ-9; S1) has nine questions with a score ranging from 0 to 3 for each question (maximum score of 27). Scores indicate mild (10-14), moderate (15-19), or severe (≥20) major depression [3,32].

The Generalized Anxiety Disorder-7 (GAD-7; S1) scale has seven questions with a score ranging from 0 to 3 for each question (maximum score of 21). Scores indicate mild (5-9), moderate (10-14), or severe (≥15) anxiety [50,51].

2.1.4. Somatic symptoms

We included the Patient Health Questionnaire-15 (PHQ-15; S1) as a standardized and validated measure [33] of somatic symptoms. The PHQ-15 is a 14-item (for men and respondents who choose 'other' as their gender) or 15-item (for women) scale for the assessment of somatic symptoms. Respondents answer whether they are 'not bothered at all' (score 0) to 'bothered a lot' (score 2) by specific symptoms such as fainting spells or back pain over the past 4 weeks (maximum score of 30). Respondents could decline to answer a question about pain or problems during sexual intercourse, in which case this item was scored as '0'. Scores represent mild (6-10), moderate (11-15), or severe (>15) somatic symptoms.

2.1.5. Bodily changes

We created a survey item for the purposes of this study that asked which, if any, bodily changes respondents have experienced for the first time or that have become worse since the onset of their pain condition (for the pain groups) or over the last 2 years (for the pain-free control group). We predefined 46 bodily changes (see S1). We chose bodily changes based on the symptoms of CRPS (e.g., weakness, swelling in a limb, change in the way the nails grow [17]) and on complaints that people with CRPS or fibromyalgia had expressed to us (e.g., poor/double vision, skin that is more susceptible to sunburn or takes longer to heal when cut, intractable rashes). We categorized all predefined bodily changes into one of the following categories, which were visible to the respondents as sub-headings in the survey: (1) vision and hearing, (2) hair, skin, and nails, (3) infection and healing, (4) urinary/intestinal function, (5) drinking and eating, (6) movement, and (7) biological responses (e.g. sweating more/less, dizziness, feeling unusually cold/hot, loss/increase of sexual desire). We summed the number of items reported within each of these categories for each respondent.

We included an 'other' option with a free-text box. We categorized the responses provided in the free-text box either into one of the existing categories or into one of the

following additional categories: (8) smell and taste (e.g., sensitivity to smell, change in taste), (9) skin sensitivity for external stimuli (e.g., hypersensitivity, numbness), (10) sensations within the body (e.g., burning sensations, pins and needles), (11) body representation (e.g., changed limb representation), (12) cognition (e.g., memory issues, word finding problems), (13) psychological (e.g., anxiety, depression), (14) energy and sleep (e.g., tiredness, sleep issues), and (15) other (e.g., change in voice, irregular periods). We summed the number of items reported within each of these categories for each respondent. Note that answers in the free-text box could include (spontaneously mentioned) *non-bodily* changes (e.g., psychological changes). It is possible that respondents who did not list any additional changes under the 'other' category might have selected some of these items if they had been presented to them as a pre-defined option. The responses provided in the free-text box were, therefore, presented separately from the predefined bodily changes, as they do not provide the same information about the overall frequency of particular categories of symptoms.

2.1.6. Sensory sensitivity

Respondents were asked which, if any, sensory stimuli give them pain, discomfort, or distress ('pain/discomfort/distress *triggers*'). We also asked those in the pain groups which, if any, sensory stimuli make their pain worse ('pain *intensifiers*'). To achieve this, we predefined 11 sensory stimuli based on complaints already identified in the literature, or that people with CRPS or fibromyalgia had expressed to us in our clinical and research work (e.g., consuming caffeine, bright lights; see S1). Additionally, we included an 'other' option with a free-text box. We summed the number of pain, discomfort, and distress triggers, and pain intensifiers that each respondent selected.

With regard to the 'other' free-text option, we categorized the responses into one of the existing categories or into one of the following additional categories: people (e.g., crowds),

stress/emotions (e.g., fighting with a beloved one), moving (e.g., exercise, bending, walking), specific posture (e.g., standing, lying, sitting), pressure (e.g., touch, anything resting or bumping into the body), vibrations (e.g., vibrations like escalators), particular materials (e.g., clothing), weather (e.g., air pressure, humidity, rain, storm), water (e.g., baths, shower, hot, cold), illness/tiredness/period (e.g., flu, lack of sleep), and other (e.g., lack of food). The responses provided in the free-text box were presented separately from the predefined triggers.

2.2 Statistical analyses

2.2.1. Respondents

We excluded respondents who had not answered all consent questions with 'yes', who were aged younger than 16 years, who did not finish at least the somatic symptoms questionnaire, and who provided inconsistent answers regarding pain duration (i.e., 'yes' on the question asking whether they experienced pain on most days for 3 months or more, and a number below 3 months on the question asking how long they have been experiencing pain). We excluded double entries, identified by comparing IP addresses and provided answers. We inspected variables for outliers. Where answers were nonsensical, (e.g., a respondent reporting pain duration per day as more than 24 hours) we replaced the data with the mean for that group for that question, and we reported the number of cases in which this was done. We assigned respondents to one of five groups based on their declared diagnoses or lack thereof: CRPS, fibromyalgia, CRPS and fibromyalgia ('CRPS+fibromyalgia'), pain control, or pain-free control. Respondents who reported not to have had pain for 3 months or more were allocated to the pain-free control group. The allocation of respondents to the CRPS, fibromyalgia, or CRPS+fibromyalgia groups were based on a respondent indicating one or both of these diagnoses, regardless of whether they indicated other pain diagnoses. Respondents were allocated to the pain control group if they did not indicate the diagnoses CRPS or fibromyalgia.

2.2.2. Demographics, depression, anxiety, and pain-related characteristics

We calculated summary statistics about demographics, depression, anxiety and pain-related characteristics. We used one-way ANOVA's and a Chi-square test (when more than 20% of cells had expected frequencies below 5, we used Fisher's exact test) to compare the groups. We used the Holm-Bonferroni method to correct for multiple comparisons for the post-hoc tests [22]. As the groups differed regarding all these variables (see results section), these variables were incorporated into the analyses addressing our research questions to control for their confounding effects. Respondents who indicated 'other' for their gender were excluded because they were too few for meaningful statistical analysis; however, we reported the descriptive statistics concerning this group for completeness.

2.2.3. Somatic symptoms, bodily changes, and sensory sensitivity

To determine whether there were any group differences in the reporting of somatic symptoms, bodily changes, and sensory sensitivity, we administered two-way ANCOVA's with Group (CRPS, fibromyalgia, CRPS+fibromyalgia, pain control, pain-free control) and Gender (male, female) as the independent variables, and PHQ-15, the number of bodily changes per category, pain triggers, discomfort triggers, distress triggers, and pain intensifiers as the dependent variables. Age, PHQ-9, GAD-7, pain duration in years, hours of pain per day, and the number of pain-related medical diagnoses were included as covariates.

We performed exploratory analyses to outline which specific bodily changes, pain/discomfort/distress triggers, and pain intensifiers were reported by respondents in the different groups (not corrected for possible confounds). We used Chi-square test (when more than 20% of cells had expected frequencies below 5, we used Fisher's exact test) to compare

the groups. For all analyses, we used the Holm-Bonferroni method to correct for multiple comparisons for the post-hoc tests.

3. Results

3.1. Demographics, depression, anxiety, and pain-related characteristics

3.1.1 Demographics

We received 2200 responses. Of these, 13 were excluded because respondents were younger than 16 years old; 485 respondents did not complete any questions about somatic symptoms, bodily changes, or sensory sensitivity; 6 respondents provided inconsistent answers regarding pain duration; and 14 responses were identified as double entries. In total, 1682 (76.5%) of responses were included in our analyses, of which 390 (23.2%) were categorised into the CRPS group, 452 (26.9%) into the fibromyalgia group, 88 (5.2%) into the CRPS+fibromyalgia group, 311 (18.5%) into the pain control group, and 441 (26.2%) into the pain-free control group. We obtained information about the location of 1060 respondents (63.0%). Most were located in the United Kingdom (59.8%), the United States of America (14.4%), Australia (6.1%), the Netherlands (5.1%), Greece (4.0%), Canada (2.1%), and Germany (1.5%). Demographic and pain characteristics are listed in Table 1. Overall, the pain-free controls were younger than the other groups. There were more females in the fibromyalgia groups (with or without CRPS) than the other groups.

3.1.2 Depression and anxiety

Respondents with CRPS, fibromyalgia, and CRPS+fibromyalgia had higher depression (PHQ-9) and anxiety (GAD-7) scores than pain controls and pain-free controls, and showed average scores consistent with *moderate* depressive and anxiety disorders (Table 1). Pain controls obtained higher depression and anxiety scores than pain-free controls, with averages consistent

with *mild* depressive and anxiety disorders. The pain-free controls showed no depressive and mild anxiety symptoms.

3.1.3. Pain duration

Respondents with fibromyalgia (with or without CRPS) reported to have experienced pain for about 13 years, which was longer than respondents with CRPS and pain controls (about 9-10 years; Table 1). Respondents with CRPS and CRPS+fibromyalgia reported a similar number of hours of pain per day, which was more than the other pain groups. This was followed by the fibromyalgia group and finally the pain controls.

3.1.4 Pain-related medical diagnoses

Respondents with CRPS+fibromyalgia reported a greater number of pain-related medical diagnoses compared to the other groups, followed by respondents with fibromyalgia, respondents with CRPS, and the pain control group (Table 1). The pain-related medical diagnoses are summarised in Table 2. In all pain groups, back pain was reported as the most frequent (comorbid) diagnosis, followed by migraine and osteoarthritis. Almost half of respondents with fibromyalgia and one third of respondents with CRPS+fibromyalgia reported comorbid irritable bowel disease. Overall, respondents with fibromyalgia (with or without CRPS) reported other diagnoses with a significantly higher frequency than the other groups across the board. Respondents with CRPS reported co-morbid diagnoses with a similar or sometimes lower frequency than the other groups.

In Supplementary Table 1, we list the diagnoses that were mentioned in the ‘other’ box. These were mainly musculoskeletal disorders (e.g., Ehlers-Danlos syndrome, psoriatic arthritis, tendonitis, spinal stenosis) and neurological disorders (e.g., nerve damage, restless legs syndrome, intracranial hypertension, neuropathy). In Supplementary Figure 1, we show

which medical practitioner(s) provided the medical diagnoses. Respondents who reported as having CRPS and/or fibromyalgia mostly reported that these diagnoses were provided by a specialist doctor and/or general practitioner. In addition, CRPS was often diagnosed by physiotherapists which was less often the case for fibromyalgia.

Information on events/injuries that triggered the pain condition and body parts in which respondents reported experiencing pain in are presented in S3 and S4, respectively.

3.2. Somatic symptoms

After adjusting for the covariates (gender, age, PHQ-9, GAD-7, pain duration, hours of pain per day, number of medical diagnoses), the five groups differed regarding somatic symptoms as measured with the PHQ-15 (Table 3). Respondents with fibromyalgia obtained scores that were significantly higher than all other groups except the CRPS+fibromyalgia group. The respondents with CRPS+fibromyalgia, had numerically higher scores than those with CRPS, pain controls, and pain-free controls, but only the difference to pain-free controls was significant. The next highest scores were for CRPS and pain controls who obtained similar scores that were also significantly higher than for the pain-free controls.

3.3. Bodily changes

Table 3 and Figure 1 show the proportion of selected bodily changes per pre-defined category for each group. When the covariates (gender, age, PHQ-9, GAD-7, pain duration in years, hours of pain per day, and the number of pain-related medical diagnoses) were controlled for, respondents with fibromyalgia reported significantly more changes in vision and hearing; urinary/intestinal function; drinking and eating; movement; and biological responses than the pain(-free) control groups. Respondents with CRPS reported more changes in hair, skin and nails; infection and healing; movement; and biological responses compared to the pain(-free)

control groups. The only category for which respondents with CRPS+fibromyalgia reported higher proportions of symptoms than respondents with only one of these conditions and both control groups was in biological responses. Exploratory analyses on individual items can be found in S5.

3.4. Sensory sensitivity

Table 3 shows the total number of pain, discomfort, and distress triggers, and pain intensifiers per group, adjusted for the covariates (gender, age, PHQ-9, GAD-7, pain duration, hours of pain per day, number of medical diagnoses). Respondents with CRPS and/or fibromyalgia reported more pain triggers and intensifiers than the other groups, whereas the pain controls did not differ from the pain-free controls. Respondents with fibromyalgia (with or without CRPS) reported a higher number of discomfort triggers, and respondents with both fibromyalgia and CRPS a higher number of distress triggers, than the other groups, although not all comparisons were significant. Exploratory analyses on individual items can be found in S6.

3.5. Exploratory analysis: Predictors of somatic sensations, bodily changes and sensory sensitivity

We performed multiple regression analyses (enter method) to evaluate the relationships between our covariates and outcome measures for respondents with CRPS or fibromyalgia. Somatic sensations were predicted by depression (PHQ-9), anxiety (GAD-7), and the number of medical diagnoses for both groups (Supplementary Table 6). The number of bodily changes was predicted by depression (PHQ-9), hours of pain per day, and the number of medical diagnoses for both groups; and additionally by pain duration for the fibromyalgia group. The number of pain/discomfort/distress triggers was predicted by the number of medical diagnoses

for both groups, and additionally by hours of pain per day for the fibromyalgia group. The number of pain intensifiers was predicted by pain duration in years for both groups, and additionally by the number of medical diagnoses for the CRPS group.

4. Discussion

The primary aim of this study was to determine whether having CRPS and/or fibromyalgia are associated with distinct profiles of bodily changes and sensory sensitivities above what could be expected due to anxiety, depression, living with chronic pain generally, and ageing.

Respondents with CRPS and/or fibromyalgia reported more pain triggers and intensifiers compared to pain(-free) controls, whereas pain controls did not differ from pain-free controls (Table 4). This indicates that higher sensory sensitivity is specifically associated with CRPS and fibromyalgia. It supports the proposed overlap between the disorders [7,34–36,58] and suggests that the diseases spread beyond neural circuits related to sensory–motor processing for the extremities.

The CNS is hypothesized to be involved in CRPS and fibromyalgia [23,24,39], with the nociceptive system being key. The nociceptive circuits become hypersensitive, increasing excitability to pain (central sensitisation). Evidence for CNS involvement includes that a subset of patients with CRPS develop hypoaesthesia, hypoalgesia, and hyperalgesia on the half of the body on the same side as the affected limb [11,30,48,49,54]. This anatomical distribution suggests CNS involvement [23]. Furthermore, there is evidence for psychophysical hyper excitability for pain stimuli in CRPS and fibromyalgia [12,39]. Sensitivity to non-somatosensory stimuli, such as visual, auditory, and olfactory [8,14,16,29,46,55], could be explained by spreading of this hypersensitivity from the periphery to higher brain areas [53]. Other factors that might be related to central sensitisation could also play a role, such as genetics, sleep disturbance, and endocrine dysfunctions [60].

Central sensitisation is also involved in other pain conditions such as irritable bowel syndrome and chronic fatigue syndrome [36,61]. This association between the different pain conditions could explain why respondents with CRPS+fibromyalgia reported more pain-related medical diagnoses (2.11 and 3.60 respectively) than the pain control group (1.63), and why respondents with CRPS+fibromyalgia reported even more diagnoses (5.00).

Our data reflected the distinct clinical phenotypes of CRPS and fibromyalgia [34,35,43]. Respondents with CRPS and/or fibromyalgia reported more changes in movement and biological responses than the pain(-free) controls. Respondents with fibromyalgia (with or without CRPS) reported more changes in vision and hearing, urinary/intestinal function, and drinking and eating; and reported a higher number of discomfort triggers than other groups. This is consistent with previous findings where people with fibromyalgia reported, for example, more hearing difficulties [57], bowel symptoms (although also found in CRPS [38]), and food intolerance [13]. However, previous studies did not account for the confounds that we included in our analyses. Therefore, our results provide stronger support for the conclusion that such changes are specific to fibromyalgia, and greater than what could be due to broader factors such as ageing and living with chronic pain generally. Respondents with CRPS (with or without fibromyalgia) reported more changes in hair, skin, and nails than other groups, consistent with previous findings [38], and that several of these items are part of the CRPS diagnostic criteria [17]. However, they also reported more changes in infection and healing (e.g., skin takes longer to heal when cut or bruised), which are not in the diagnostic criteria.

These findings imply that the sensitivity changes in CRPS and fibromyalgia are broader than those that relate to nociceptive systems [36]. It is not clear why some changes relate to CRPS and others to fibromyalgia. Typically, peripheral tissue damage causes a localized sensitisation process in CRPS whereas this is widespread in fibromyalgia. However, with time, CRPS pain can become more widespread and eventually fulfil the criteria for fibromyalgia

[36]. In our sample, respondents with CRPS frequently reported pain in body parts other than that affected by CRPS (in line with [37]). We did not see a clear relationship between pain chronicity and number of bodily changes. Disease progression is therefore not simply a predictor of the likelihood of reporting these changes. We did observe that the number of reported *pain intensifiers* was predicted by pain duration in years for both groups. We note that in CRPS, a dissociation can be made between 'warm' and 'cold' subtypes, with a higher contribution of inflammatory mechanisms to the former [6]. Results could, therefore, also be explained by differences between these subtypes.

Compared to respondents with only CRPS or fibromyalgia, respondents with both reported a higher proportion of changes in biological responses, and a higher number of discomfort and distress triggers. As some of the changes in biological responses relate more to CRPS (e.g., one body part feeling unusually cold/hot) and others relate more to fibromyalgia (e.g., dizziness), this category reflects most strongly that people with both CRPS and fibromyalgia suffer from a wider range of symptoms than people who only have one of the conditions. However, there was no added distress for this group: they did not score higher regarding depression, anxiety, pain duration, hours of pain per day, or pain intensity. Because this group was small (n = 88), no firm conclusions can be drawn.

Overall, our analyses of demographic, clinical, and pain-related characteristics are consistent with previous research. Respondents with pain had higher depression and anxiety than respondents without pain [20,40], with highest scores for respondents with CRPS and/or fibromyalgia [5,38]. There was a higher proportion of females in the pain groups than the pain-free control group [5,20,38,40]. The onset of CRPS was mostly associated with physical trauma [35,38,58], and fibromyalgia with stressful situations (although this is not always found in literature [18,35,45]). Respondents with CRPS most frequently reported their limb(s) as being most painful, whereas respondents with fibromyalgia reported widespread pain [58].

Respondents with pain reported more somatic symptoms (PHQ-15) than pain-free controls. Furthermore, respondents with fibromyalgia had the highest PHQ-15 scores, consistent with the fact that several of the items are in the fibromyalgia diagnostic criteria [56].

4.1. Limitations and strengths

Our study has some limitations. First, it is possible that people who experience unusual bodily sensations were more likely to respond, because we mentioned that the survey was about mood, bodily changes and other sensations. We conducted an online survey in order to include patients who live distant from our lab and/or are not able to travel. However, people with chronic pain possibly become more active on social media or in patient support groups once they have experienced their condition for a prolonged period. Future studies should focus on attaining unbiased samples. Second, groupings were based on self-reported diagnoses. To mitigate this, we asked respondents to report where they received their diagnoses. Most respondents reported receiving their diagnoses from an appropriately qualified practitioner. Third, we asked respondents with chronic pain to report their bodily changes and sensory sensitivity since the onset of their pain condition, whereas the pain-free controls reported the same over the past two years., because we estimated this was a reasonable time to have an accurate impression. However, the average duration of pain in our patient groups was 8.66-13.37 years, meaning that they were responding with regards to a longer time period. We controlled for this by including pain duration as a covariate (set to 0 for pain-free controls). Fourth, we distributed the survey internationally, and some of the English terms might not be consistent across countries or fully understood by non-native speakers. Finally, with regard to bodily changes, pain/discomfort/distress triggers, and pain intensifiers, we only recorded the presence or absence of symptoms. Thus, our results report on differences in the *number of distinct* bodily changes and sensory sensitivities reported by different patient groups and we are unable to

make inferences about the *severity, intensity, or frequency (e.g. times felt per day)* of these symptoms. However, results from these questions were broadly consistent with the results of the PHQ-15, which does give an overall scaled score, in that respondents with fibromyalgia had higher PHQ-15 scores and reported more bodily changes and sensory sensitivities.

Our study also has several strengths. First, our sample size was large enough to compare the number and nature of self-reported bodily changes and sensory sensitivity between respondents with CRPS, fibromyalgia, other chronic pain conditions, and pain-free controls, while controlling for possible confounds. Second, this was the first study to assess *discomfort* and *distress* triggers, in addition to pain triggers. We found different patterns of results across these categories. Indeed, respondents with pain were more likely to report external stimuli as causing discomfort or distress than pain, which likely represents a negative effect on their quality of life that has not previously been considered. Therefore, these categories seem important to include in future studies. Third, this was the first study that separately evaluated respondents who self-reported as having both CRPS and fibromyalgia, demonstrating that the clinical and sensory profile of such patients is broadly similar to the overlap of respondents with only one of these conditions.

4.2. Conclusions

Respondents with CRPS and/or fibromyalgia reported more bodily changes and a greater number of sensory sensitivities than pain(-free) control groups.. These group differences cannot be attributed to sex differences, ageing, depression, anxiety, pain duration in years, hours of pain per day, and the number of pain-related medical diagnoses. Note that participants rated items subjectively and we did not collect any objective measures to support these ratings.

Acknowledgements: The authors declare that they have no conflict of interest. Antonia ten Brink was supported by a Rubicon grant (019.173SG.019) from the Netherlands Organisation for Scientific Research (NWO).

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Table 1. Demographics, depression, anxiety, and pain-related characteristics, means (SD) and percentages, split per group.

	N	**CRPS**	*N*	**Fibromyalgia**	*N*	**CRPS+ Fibromyalgia**	*N*	**Pain controls**	*N*	**Pain-free controls**	**Statistics**
Age, in years	390	45.64 (12.63)[4,5]	452	47.01 (12.04)[4,5]	88	45.65 (11.34)[4,5]	311	41.63 (16.71)[1,2,3,5]	441	34.63 (16.30)[1,2,3,4]	$F(4) = 50.82$, $p < .001$
Gender[a]	390		452		88		311		441		$\chi^2(4) = 98.27$, $p < .001$
- Female		346 (88.7%)[2,4,5]		421 (93.1%)[1,4,5]		84 (95.5%)[4,5]		247 (79.4%)[1,2,3,5]		320 (72.6%)[1,2,3,4]	
- Male		44 (11.3%)		25 (5.5%)		4 (4.5%)		58 (18.6%)		120 (27.2%)	
- Other		0		6 (1.3%)		0		6 (1.9%)		1 (0.2%)	
PHQ-9 (0-27)	314	15.62 (6.52)[4,5]	362	16.33 (6.06)[4,5]	70	16.73 (6.26)[4,5]	259	10.84 (7.00)[1,2,3,5]	387	5.99 (4.90)[1,2,3,4]	$F(4) = 180.94$, $p < .001$
GAD-7 (0-21)	314	10.66 (6.06)[4,5]	362	11.01 (5.86)[4,5]	70	11.09 (5.95)[4,5]	259	7.90 (5.99)[1,2,3,5]	387	4.93 (4.58)[1,2,3,4]	$F(4) = 73.03$, $p < .001$
Pain duration, in years	388	8.66 (7.95)[2,3]	452	13.37 (10.60)[1,4]	87	12.54 (10.02)[1]	310	9.72 (10.39)[2]	-	-	$F(3) = 18.90$, $p < .001$
Hours of pain per day[b]	390	18.49 (6.86)[2,4]	452	16.37 (7.17)[1,3,4]	88	19.57 (6.39)[2,4]	311	10.40 (8.06)[1,2,3]	-	-	$F(3) = 83.94$, $p < .001$
Number of pain-related medical diagnoses	390	2.11 (1.57)[2,3,4]	452	3.60 (2.05)[1,3,4]	88	5.00 (3.49)[1,2,4]	311	1.63 (1.82)[1,2,3]	-	-	$F(3) = 110.40$, $p < .001$

Abbreviations: Patient Health Questionnaire-9, PHQ-9; Generalized Anxiety Disorder-7, GAD-7.

Note. The number of respondents differ per variable, as some respondents closed the survey before finishing it and only answers provided to that point were included.

[a]We did not include the 'other' group in the statistical comparison of gender, as the expected counts would be less than 5 in some cells.

[b]One respondent in the CRPS group and one in the fibromyalgia group provided pain durations per day as more than 24 hours. Their values were replaced by the group mean.

Group mean differed significantly from [1]CRPS, [2]fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls.

Table 2. Numbers and percentages of medical diagnoses split by group. Note that respondents could report multiple diagnoses, thus percentages do not sum to 100.

	CRPS (*N* = 390)	**Fibromyalgia (*N* = 452)**	**CRPS+ Fibromyalgia (*N* = 88)**	**Pain controls (*N* = 311)**	**Statistics**
CRPS	390 (100%)	0	88 (100%)	0	-
Fibromyalgia	0	452 (100%)	88 (100%)	0	-
Back pain	80 (20.5%)[2,3,4]	187 (41.4%)[1,4]	46 (52.3%)[1,4]	92 (29.6%)[1,2,3]	$\chi^2(3) = 58.52$, $p < .001$
Migraine	53 (13.6%)[2,3]	144 (31.9%)[1,4]	27 (30.7%)[1,4]	36 (11.6%)[2,3]	$\chi^2(3) = 66.77$, $p < .001$
Osteoarthritis	47 (12.1%)[2,3,4]	129 (28.5%)[1,4]	28 (31.8%)[1,4]	60 (19.3%)[1,2,3]	$\chi^2(3) = 40.63$, $p < .001$
Irritable Bowel Disease	34 (8.7%)[2,3]	183 (40.5%)[1,4]	27 (30.7%)[1,4]	26 (8.4%)[2,3]	$\chi^2(3) = 169.00$, $p < .001$
Neuralgia	30 (7.7%)[3]	45 (10.0%)[4]	17 (19.3%)[1,4]	12 (3.9%)[2,3]	$\chi^2(3) = 23.70$, $p < .001$
Hypermobility condition	27 (6.9%)[2]	79 (17.5%)[1]	12 (13.6%)	34 (10.9%)	$\chi^2(3) = 22.45$, $p < .001$
Plantar fasciitis	17 (4.4%)[2]	56 (12.4%)[1,4]	9 (10.2%)	10 (3.2%)[2]	$\chi^2(3) = 30.61$, $p < .001$
Rheumatoid Arthritis	13 (3.3%)[2,3,4]	37 (8.2%)[1]	11 (12.5%)[1]	25 (8.0%)[1]	$\chi^2(3) = 13.75$, $p = .003$
Endometriosis	11 (2.8%)[3]	29 (6.4%)	11 (12.5%)[1,4]	10 (3.2%)[3]	$\chi^2(3) = 18.59$, $p < .001$
Cluster headache	7 (1.8%)[2]	27 (6.0%)[1,4]	4 (4.5%)	5 (1.6%)[2]	$\chi^2(3) = 15.27$, $p = .002$
Stomach ulcer	6 (1.5%)	12 (2.7%)	2 (2.3%)	2 (0.6%)	$\chi^2(3) = 4.55$, $p = .208$
Crohn's Disease	2 (0.5%)	2 (0.4%)	0	0	$p = .679$[a]
Multiple Sclerosis	1 (0.3%)	1 (0.2%)	2 (2.3%)	3 (1.0%)	$p = .059$[a]
Other (one or more other pain-related diagnosis)	69 (17.7%)[2,4]	162 (35.8%)[1]	24 (27.3%)	123 (39.5%)[1]	$\chi^2(3) = 48.75$, $p < .001$
None	0	0	0	89 (28.6%)	-

Group mean differed significantly from [1]CRPS, [2]fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls. [a]Tested with a Fisher's Exact Test.

Table 3. Somatic symptoms, bodily changes and sensory sensitivity scores. Means (SE) are depicted per group, taking into account the covariates (gender, age, PHQ-9, GAD-7, pain duration, hours of pain per day, number of medical diagnoses).

	CRPS (*N* = 312)	**Fibromyalgia (*N* = 356)**	**CRPS+ Fibromyalgia (*N* = 69)**	**Pain controls (*N* = 253)**	**Pain-free controls (*N* = 386)**	**Statistics**
Somatic symptoms						
PHQ-15	11.27 (0.33)[2,5]	14.45 (0.43)[1,4,5]	12.57 (1.05)[5]	11.10 (0.29)[2,5]	9.28(0.28)[1,2,3,4]	$F(4) = 21.83$, $p < .001$
Bodily changes (proportion of selected items per category)						
Vision and hearing	0.23 (0.02)[2]	0.35 (0.02)[1,4,5]	0.35 (0.06)[4]	0.18 (0.02)[2,3,5]	0.25 (0.02)[2,4]	$F(4) = 11.15$, $p < .001$
Hair, skin, and nail	0.38 (0.02)[2,4,5]	0.19 (0.02)[1,3]	0.48 (0.05)[2,4,5]	0.15 (0.01)[1,3,5]	0.24 (0.01)[1,3,4]	$F(4) = 40.63$, $p < .001$
Infection and healing	0.45 (0.03)[4,5]	0.35 (0.04)[3]	0.69 (0.10)[2,4,5]	0.29 (0.03)[1,3]	0.31 (0.03)[1,3]	$F(4) = 6.40$, $p < .001$
Digestive function	0.25 (0.02)	0.33 (0.03)[4]	0.23 (0.06)	0.22 (0.02)[2]	0.24 (0.02)	$F(4) = 3.09$, $p = .015$
Drinking and eating	0.21 (0.05)	0.27 (0.02)[4]	0.21 (0.05)	0.18 (0.01)[2]	0.22 (0.01)	$F(4) = 3.34$, $p = .010$
Movement	0.56 (0.02)	0.49 (0.03)	0.59 (0.07)	0.40 (0.02)	0.30 (0.02)	$F(4) = 18.49$, $p < .001$
Biological responses	0.34 (0.01)[3,4,5]	0.31 (0.02)[3,4,5]	0.46 (0.05)[1,2,4,5]	0.19 (0.01)[1,2,3]	0.22 (0.20)[1,2,3]	$F(4) = 20.97$, $p < .001$
Sensory sensitivity (number of selected items)						
Pain triggers	2.19 (0.16)[4,5]	1.74 (0.21)[4]	2.94 (0.51)[4,5]	1.03 (0.14)[1,2,3]	1.29 (0.14)[1,2,3]	$F(4) = 8.95$, $p < .001$
Discomfort triggers	2.48 (0.21)[2]	3.67 (0.28)[1,4]	4.18 (0.68)[4]	2.11 (0.19)[2,3,5]	2.98 (0.19)[4]	$F(4) = 8.19$, $p < .001$
Distress triggers	0.98 (0.18)[3]	1.10 (0.23)	2.68 (0.56)[1,4]	0.89 (0.15)[3,5]	1.52 (0.15)[4]	$F(4) = 4.57$, $p = .001$
Pain intensifiers	3.69 (0.21)[4]	3.14 (0.28)[4]	4.58 (0.70)[4]	2.19 (0.21)[1,2,3]	-	$F(3) = 9.92$, $p < .001$

Abbreviations: Patient Health Questionnaire-15, PHQ-15;

Group mean differed significantly from [1]CRPS, [2]fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls.

Table 4. Summary of group differences found for somatic symptoms, bodily changes, and sensory sensitivity. The summary reflects the statistical differences found after controlling for our covariates (gender, age, PHQ-9, GAD-7, pain duration, hours of pain per day, number of medical diagnoses).

Comparison	Results
Pain controls vs pain-free controls	Pain controls reported more somatic symptoms and movement-related changes than pain-free controls. Pain-free controls reported more vision & hearing changes, hair, skin & nail changes, discomfort triggers, and distress triggers than pain controls.
CRPS vs pain(-free) controls	Respondents with CRPS reported more somatic symptoms, hair, skin & nail changes, infection & healing changes, movement-related changes, changes in biological responses, pain triggers, and pain intensifiers than pain(-free) controls.
Fibromyalgia vs pain(-free) controls	Respondents with fibromyalgia reported more somatic symptoms, vision & hearing changes, urinary/intestinal function changes, drinking & eating changes, movement-related changes, changes in biological responses, pain triggers, discomfort triggers, and pain intensifiers than pain(-free) controls.
CRPS vs fibromyalgia	Respondents with CRPS reported more hair, skin & nail changes; and infection & healing changes than respondents with fibromyalgia. Respondents with fibromyalgia reported more somatic symptoms, vision & hearing changes and discomfort triggers than respondents with CRPS.
CRPS+fibromyalgia vs CRPS or fibromyalgia only	Respondents with CRPS+fibromyalgia reported more changes in biological responses than respondents with either CRPS or fibromyalgia. Respondents with CRPS+fibromyalgia reported more vision & hearing changes and distress triggers than respondents with CRPS, which did not differ from respondents with fibromyalgia. Respondents with CRPS+fibromyalgia reported more hair, skin & nail changes; and infection & healing changes than respondents with fibromyalgia, which did not differ from respondents with CRPS.

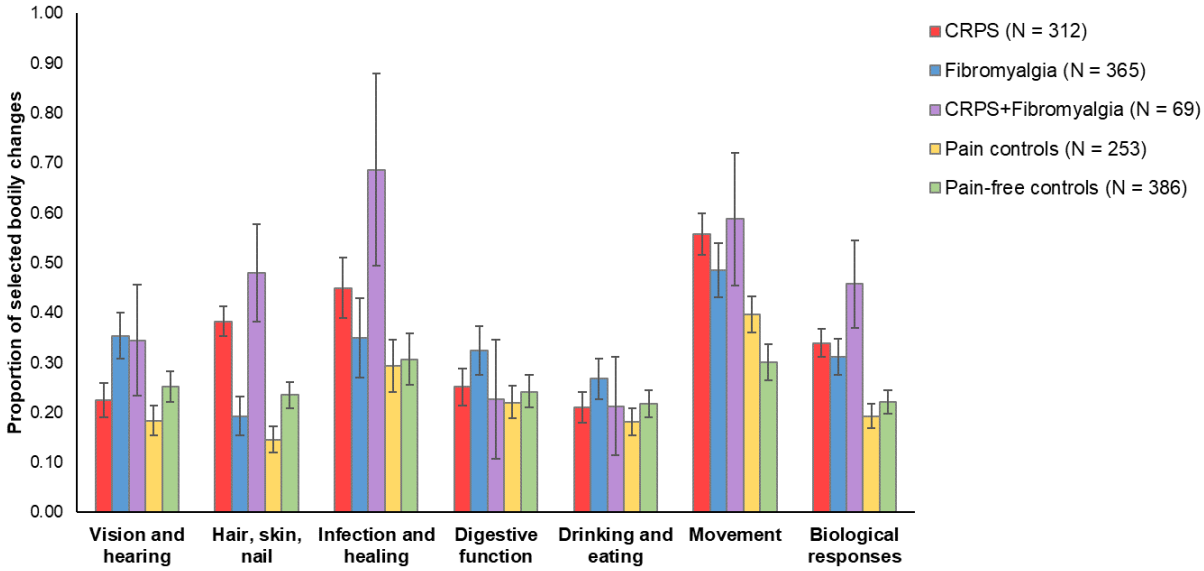


Figure 1. The proportion of selected bodily changes per category taking into account our covariates (gender, age, PHQ-9, GAD-7, pain duration, hours of pain per day, number of medical diagnoses). Error bars depict 95% confidence intervals.

Supplementary material

S1. Survey questions

Demographic information

What is your age in years?
▼ Under 16 ... 100 or older

What is your gender?
▼ Male, Female, Other

Pain-related characteristics

Have you been experiencing pain on most days for three months or more?

- ○ YES
- ○ NO

On average, for how many **hours** per day do you normally feel pain? Please answer using **numbers**. For example, half an hour would be ".5", and two hours would be "2".
Hours per day _____

For approximately how long have you been experiencing pain? Please answer in **years** and **months**. For example, 6 months would be “0" years and "6" months.
Years _____
Months _____

Where in your body have you felt pain **over the last week**. You can select as many responses as you like so please select all that apply.

- ○ Left arm and/or hand
- ○ Left leg and/or foot
- ○ Right arm and/or hand
- ○ Right leg and/or foot
- ○ Back
- ○ Stomach/abdomen
- ○ Chest
- ○ Groin/genitals
- ○ Neck

- ○ Head
- ○ Other (Please specify. You can specify more than one thing if you wish)

For each of the body parts that you have selected, please rate your **average** level of pain that you have experienced in that body part **over the last week**.

No pain Worst pain imaginable
0 1 2 3 4 5 6 7 8 9 10

Please rate your average level of pain that you have experienced in your body OVERALL over the last week (that is, averaged across all your painful body parts).

No pain Worst pain imaginable
0 1 2 3 4 5 6 7 8 9 10

Have you received a medical diagnosis for your pain condition? Here, a medical diagnosis is a diagnosis that has been determined by a medical practitioner such as a GP, specialist doctor (e.g. rheumatologist or pain specialist), physiotherapist, occupational therapist, or nurse.

- ○ YES
- ○ NO

Please select all medical diagnoses that you have received for your pain condition.

- ○ Complex Regional Pain Syndrome (also known as Reflex Sympathetic Dystrophy, Causalgia, or Sudeck's syndrome)
- ○ Rheumatoid Arthritis
- ○ Osteoarthritis
- ○ Plantar fasciitis
- ○ Fibromyalgia
- ○ Hypermobility
- ○ Back pain
- ○ Migraine

- ○ Cluster Headache
- ○ Multiple Sclerosis
- ○ Neuralgia
- ○ Stomach ulcer
- ○ Endometriosis
- ○ Irritable Bowel Disease
- ○ Crohn's Disease
- ○ Other (Please specify. You can specify more than one thing if you wish)_____
- ○ I have not received any diagnosis for my pain condition

You answered that you have received a medical diagnosis of *[diagnosis that was selected]*. Which medical practitioner diagnosed you with this condition (if you recall). Please select ALL that apply.

- ○ GP
- ○ Specialist doctor (e.g. rheumatologist or pain specialist)
- ○ Physiotherapist
- ○ Occupational therapist
- ○ Nurse
- ○ Other (Please specify)_____
- ○ Don't know/can't remember

Was there an event or injury that triggered the onset of your pain condition(s)?

- ○ YES
- ○ NO

What was the event or injury that triggered the onset of your pain condition(s)?

- ○ Sprain
- ○ Fracture
- ○ Dislocation

○ Surgery

○ Infection

○ Childbirth

○ Stressful situation such as bereavement, divorce, or loss of job (please specify. You can specify more than one thing if you wish) _____

○ Other (Please specify. You can specify more than one thing if you wish) _____

Bodily changes

Have you experienced any of the following [since the onset of your pain condition/over the past two years]*. Please only select those things that have **started to bother you** or have **become worse** since the onset of your pain condition. Select ANY that apply.
** Respondents only saw one of the two options based on whether they reported to have chronic pain or not.*

○ Blurred vision

○ Needing to change your glasses or contact lens prescription more often

○ Peripheral vision loss

○ Sensitivity to bright lights

○ Hearing loss

○ Tinnitus (Ringing in the ears)

○ Sensitivity to loud noises

○ Losing hair on your head

○ Losing hair on parts of your body other than your head

○ Extra hair growth on any part of your body

○ Skin rashes

○ Being more susceptible to sunburn

○ Changes in the texture of your skin

○ Changes in skin colour

○ Swelling (edema) in any body part

○ Changes in the nails of your hands (e.g. growing faster or slower, or being more brittle)

○ Changes in your toenails (e.g. growing faster or slower, or being more brittle)

○ Allergic reactions on the skin

○ Increased susceptibility to illness (for example, becoming more frequently ill, or taking longer to recover from illness)

○ Finding your skin takes longer to heal when cut or bruised

○ Needing to urinate more often, or finding it difficult from stopping yourself urinate when you ‘need to go’

○ Needing to urinate less often, or finding it difficult to urinate

○ Loose bowels, diarrhoea, or needing to defecate more often

○ Constipation

○ Having a “sensitive stomach”

○ Nausea

○ Increase in weight

○ Decrease in weight

○ Allergic reactions to food and drink

○ Decreased alcohol tolerance

○ Increased alcohol tolerance

○ Weakness in any part of your body

○ Tremor in any part of your body

○ Problems with balance

○ Falling more frequently

○ Difficulties walking

○ Sweating more

○ Sweating less

○ Dizziness

○ Hay fever

- ○ Loss of sexual desire
- ○ Increased sexual desire
- ○ Feeling unusually cold, or finding it difficult to get warm when you are cold
- ○ Feeling unusually hot, or finding it difficult to cool down when you are hot
- ○ Please specify anything else that you have experienced. Even if you have experienced a change to your body or its sensations that you think is odd, unusual, or sounds "a bit crazy", we are interested in hearing about it. You can specify more than one thing if you wish. In the next question you will have an opportunity to explain more about the changes and how they make you feel if you wish. Here, please just list any additional changes if there are any. _____

Sensory sensitivity

Do any of the following give you pain? Please select ANY that apply.*

Do any of the following give you discomfort? Please select ANY that apply.*

Do any of the following give you distress? Please select ANY that apply.*

Do any of the following make your pain worse? Please select ANY that apply.*

** The list of items below was used for each of the previous four questions:*

- ○ Caffeine
- ○ Alcohol
- ○ Bright lights
- ○ Flashing lights
- ○ High-contrast images, such as black and white stripes spaced close together
- ○ Loud or unpleasant noises
- ○ The touch of clothing/water/breeze
- ○ Particular foods. If yes, please specify _____
- ○ Particular smells. If yes, please specify _____
- ○ Cold weather. if yes, then please specify from what temperature your pain starts_____
- ○ Warm or hot weather. If yes, then please specify from what temperature your pain starts _____
- ○ Other (Please specify. You can specify more than one thing if you wish)_____

Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half days	Nearly every day
Little interest or pleasure in doing things	○	○	○	○
Feeling down, depressed, or hopeless	○	○	○	○
Trouble falling/staying asleep, sleeping too much	○	○	○	○
Feeling tired or having little energy	○	○	○	○
Poor appetite or overeating	○	○	○	○
Feeling bad about yourself – or that you are a failure or have let yourself or your family down	○	○	○	○
Trouble concentrating on things, such as reading the newspaper or watching television	○	○	○	○
Moving or speaking so slowly that other people could have noticed	○	○	○	○
Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	○	○	○	○
Thoughts that you would be better off dead or of hurting yourself in some way	○	○	○	○

Generalized Anxiety Disorder (GAD-7)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half days	Nearly every day
Feeling nervous, anxious, or on edge	○	○	○	○
Not being able to stop or control worrying	○	○	○	○
Worrying too much about different things	○	○	○	○
Trouble relaxing	○	○	○	○
Being so restless that it's hard to sit still	○	○	○	○
Becoming easily annoyed or irritable	○	○	○	○
Feeling afraid as if something awful might happen	○	○	○	○

Patient Health Questionnaire-15 (PHQ-15)

During the past 4 weeks, how much have you been bothered by any of the following problems?

	Not bothered at all	Bothered a little	Bothered a lot
Stomach pain	○	○	○
Back pain	○	○	○
Pain in your arms, legs, or joints (knees, hips, etc.)	○	○	○
Menstrual cramps or other problems with your periods	○	○	○
Headaches	○	○	○
Chest pain	○	○	○
Dizziness	○	○	○
Fainting spells	○	○	○
Feeling your heart pound or race	○	○	○
Shortness of breath	○	○	○
Constipation, loose bowels, or diarrhoea	○	○	○
Nausea, gas, or indigestion	○	○	○
Feeling tired or having low energy	○	○	○
Trouble sleeping	○	○	○

	Not bothered at all	Bothered a little	Bothered a lot	Prefer not to say	Not applicable
Pain or problems during sexual intercourse	○	○	○	○	○

S2. 'Other' pain-related medical diagnoses

Supplementary Table 1. Numbers and percentages of people who reported one or more pain-related medical diagnoses in the 'other' box, that were grouped in the categories listed below. We categorized the diagnoses based on the coding system for medical research categorisation, outlined by UK Clinical Research Collaboration (https://hrcsonline.net/health-categories/). Note that these also include spontaneously reported *non pain-related* medical diagnoses, even though this was not asked for.

	CRPS (*N* = 390)	**Fibromyalgia (*N* = 452)**	**CRPS+ Fibromyalgia (*N* = 88)**	**Pain controls (*N* = 311)**
Musculoskeletal	41 (10.5%)	76 (16.8%)	10 (11.3%)	59 (19.0%)
Neurological	11 (2.8%)	27 (6.0%)	8 (9.0%)	37 (11.9%)
Inflammatory and immune system	8 (2.1%)	23 (5.1%)	5 (5.6%)	8 (2.6%)
Oral and gastrointestinal	6 (1.5%)	14 (3.1%)	5 (5.6%)	6 (1.9%)
Blood	4 (1.0%)	1 (0.2%)	2 (2.3%)	1 (0.3%)
Injuries and accidents	3 (0.8%)	4 (0.9%)	2 (2.3%)	14 (4.5%)
Reproductive health and childbirth	2 (0.5%)	8 (1.8%)	2 (2.3%)	4 (1.3%)
Renal and urogenital	2 (0.5%)	3 (0.7%)	2 (2.3%)	1 (0.3%)
Metabolic and endocrine	1 (0.3%)	7 (1.5%)	1 (1.1%)	2 (0.6%)
Cardiovascular	1 (0.3%)	4 (0.9%)	3 (3.4%)	1 (0.3%)
Skin	1 (0.3%)	2 (0.4%)	0	4 (1.3%)
Mental health	1 (0.3%)	2 (0.4%)	0	2 (0.6%)
Respiratory	0	3 (0.7%)	2 (2.3%)	2 (0.6%)
Cancer and neoplasms	0	1 (0.2%)	0	4 (1.3%)
Congenital disorders	0	1 (0.2%)	0	0
Eye	0	1 (0.2%)	0	0
Infection	0	0	2 (2.3%)	1 (0.3%)
Ear	0	0	1 (1.1%)	0
Stroke	0	0	0	0
Disputed aetiology and other	5 (1.3%)	33 (7.3%)	1 (1.1%)	17 (5.5%)

S3. Events/injuries that triggered the pain condition

Fracture and surgery were reported more often by respondents with CRPS than respondents without CRPS, followed by sprain and dislocation (Supplementary Table 2). A stressful situation was reported more often by respondents with fibromyalgia than by respondents without fibromyalgia, followed by infection and childbirth. In general, respondents with CRPS+fibromyalgia tended to report the same inciting events as reported by respondents with only one of these conditions.

Supplementary Table 2. Numbers and percentages of events/injuries that triggered the pain condition. Note that respondents could report multiple events/injuries, thus percentages do not sum to 100.

	CRPS (*N* = 390)	**Fibromyalgia (*N* = 452)**	**CRPS+ Fibromyalgia (*N* = 88)**	**Pain controls (*N* = 311)**	**Statistics**
None	27 (6.9%)[2,4]	227 (50.2%)[1,3]	10 (11.4%)[2,4]	154 (49.5%)[1,3]	$\chi^2(3) = 234.91$, $p < .001$
Fracture	129 (33.1%)[2,4]	20 (4.4%)[1,3,4]	26 (29.5%)[2,4]	27 (8.7%)[1,2,3]	$\chi^2(3) = 151.90$, $p < .001$
Surgery	126 (32.3%)[2,4]	32 (7.1%)[1,3]	34 (38.6%)[2,4]	33 (10.6%)[1,3]	$\chi^2(3) = 126.77$, $p < .001$
Sprain	71 (18.2%)[2,4]	19 (4.2%)[1,3]	13 (14.8%)[2]	23 (7.4%)[1]	$\chi^2(3) = 49.91$, $p < .001$
Dislocation	29 (7.4%)[2]	5 (1.1%)[1,3,4]	8 (9.1%)[2]	13 (4.2%)[2]	$\chi^2(3) = 24.67$, $p < .001$
Stressful situation	28 (7.2%)[2,3]	113 (25.0%)[1,4]	15 (17.0%)[1]	28 (9.0%)[2]	$\chi^2(3) = 63.80$, $p < .001$
Infection	13 (3.3%)[2]	44 (9.7%)[1,4]	6 (6.8%)	10 (3.2%)[2]	$\chi^2(3) = 20.83$, $p < .001$
Childbirth	3 (0.8%)[2,3]	26 (5.8%)[1]	7 (8.0%)[1]	10 (3.2%)	$\chi^2(3) = 19.39$, $p < .001$
Other	116 (29.7%)[2]	95 (21.0%)[1,3,4]	31 (35.2%)[2]	92 (29.6%)[2]	$\chi^2(3) = 13.79$, $p = .003$

Group mean differed significantly from [1]CRPS, [2]fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls.

S4. Body parts in which respondents reported experiencing pain in

Most respondents with CRPS reported the leg and/or foot as being most painful, followed by the arm and/or hand (Supplementary Table 3). However, respondents with CRPS also often reported experiencing pain in parts of their body other than their limbs, especially the back, neck, and head. Respondents with fibromyalgia most frequently reported the back, neck, and head as being most painful, and the majority reported some pain in these body areas. Respondents with CRPS+fibromyalgia reported the leg and/or foot as being most painful, followed by the arm and/or hand, although they did experience pain in many other body parts as well, which was comparable with the fibromyalgia only group. More pain controls reported the back as being most painful, and approximately two-thirds of respondents in this group reported some pain in this area. The overall pain intensity for the most painful body part differed between groups, $F(4) = 69.11$, $p < .001$. Respondents with fibromyalgia (with or without CRPS) reported the highest pain intensity. Respondents with only CRPS reported higher pain intensity than pain controls.

Supplementary Table 3. Numbers and percentages of the body parts where respondents reported any pain in the past week, and the average pain intensity reported across any painful body part, the most painful body parts over the past week, and the average pain intensity reported for the most painful body part. Note that respondents could report multiple body parts, thus percentages do not sum to 100.

	CRPS (*N* = 390)				**Fibromyalgia (*N* = 452)**				**CRPS+Fibromyalgia (*N* = 88)**				**Pain controls (*N* = 311)**			
	Experienced pain	**Intensity**	**Most painful**	**Intensity most painful**	**Experienced pain**	**Intensity**	**Most painful**	**Intensity most painful**	**Experienced pain**	**Intensity**	**Most painful**	**Intensity most painful**	**Experienced pain**	**Intensity**	**Most painful**	**Intensity most painful**
Left leg and/or foot	193 (49.5%)	7.05 (2.05)	100 (25.6%)	7.87 (1.76)	359 (79.4%)	6.15 (2.00)	43 (9.5%)	8.20 (1.67)	72 (81.8%)	7.24 (2.18)	29 (33.0%)	8.51 (1.56)	124 (39.9%)	4.96 (2.04)	32 (10.3%)	6.48 (1.79)
Right leg and/or foot	210 (53.8%)	7.04 (2.04)	124 (31.8%)	7.68 (1.82)	370 (81.9%)	6.23 (1.98)	47 (10.4%)	8.43 (1.46)	58 (65.9%)	7.46 (1.84)	20 (22.7%)	8.81 (1.38)	141 (45.3%)	5.09 (2.11)	43 (13.8%)	6.27 (2.10)

Left arm and/or hand	150 (38.5%)	6.27 (2.22)	60 (15.4%)	7.17 (2.35)	345 (76.3%)	5.61 (1.94)	21 (4.6%)	7.97 (1.81)	62 (70.5%)	6.25 (2.43)	15 (17.0%)	8.73 (1.72)	90 (28.9%)	4.64 (2.29)	14 (4.5%)	7.41 (2.36)
Right arm and/or hand	151 (38.7%)	6.40 (2.07)	62 (15.9%)	7.12 (2.08)	359 (79.4%)	5.91 (2.04)	34 (7.5%)	8.43 (1.46)	58 (65.9%)	6.11 (2.47)	12 (13.6%)	9.27 (0.74)	96 (30.9%)	4.49 (2.09)	24 (7.7%)	5.92 (1.90)
Back	176 (45.1%)	6.36 (2.32)	37 (9.5%)	8.46 (1.73)	415 (91.8%)	7.12 (2.02)	152 (33.6%)	8.33 (1.61)	75 (85.2%)	6.85 (2.18)	14 (15.9%)	9.01 (1.08)	203 (65.3%)	5.38 (2.14)	87 (28.0%)	6.13 (2.12)
Stomach/abdomen	78 (20.0%)	5.46 (2.35)	12 (3.1%)	9.06 (0.97)	260 (57.5%)	5.77 (2.20)	31 (6.9%)	8.37 (1.29)	42 (47.7%)	6.30 (2.16)	7 (8.0%)	8.99 (1.24)	85 (27.3%)	5.39 (2.09)	32 (10.3%)	6.77 (1.81)
Chest	56 (14.4%)	5.30 (2.32)	7 (1.8%)	7.29 (2.55)	219 (48.5%)	5.53 (2.31)	20 (4.4%)	8.60 (1.26)	29 (33.0%)	5.65 (2.34)	2 (2.3%)	9.25 (0.35)	45 (14.5%)	4.27 (2.02)	5 (1.6%)	6.62 (1.39)
Groin/genitals	44 (11.3%)	5.64 (2.17)	6 (1.5%)	7.22 (1.71)	117 (25.9%)	5.66 (2.40)	9 (2.0%)	8.29 (1.96)	17 (19.3%)	6.28 (2.32)	3 (3.4%)	9.83 (0.29)	30 (9.6%)	4.78 (2.14)	4 (1.3%)	6.90 (0.89)
Neck	131 (33.6%)	5.96 (2.23)	24 (6.2%)	8.01 (1.81)	401 (88.7%)	6.61 (2.14)	118 (26.1%)	8.39 (1.33)	63 (71.6%)	6.21 (2.46)	10 (11.4%)	9.07 (1.09)	133 (42.8%)	5.09 (2.22)	35 (11.3%)	6.26 (2.11)
Head	107 (27.4%)	5.93 (2.31)	18 (4.6%)	7.79 (1.94)	357 (79.0%)	6.31 (2.17)	76 (16.8%)	8.47 (1.49)	49 (55.7%)	5.96 (2.43)	6 (6.8%)	9.70 (0.40)	97 (31.2%)	5.75 (2.14)	40 (12.9%)	7.09 (1.82)
Other	60 (15.4%)	6.96 (2.24)	27 (6.9%)	8.36 (1.47)	138 (30.5%)	7.73 (1.73)	72 (15.9%)	8.33 (1.50)	26 (29.5%)	7.15 (2.10)	7 (8.0%)	9.34 (1.19)	66 (21.2%)	5.79 (2.50)	38 (12.2%)	6.59 (2.49)
Overall pain intensity	-	6.63 (2.14)	-	7.49 (1.88)	-	7.02 (1.55)	-	8.18 (1.42)	-	7.44 (1.60)	-	8.44 (1.43)	-	5.18 (2.18)	-	6.28 (2.02)

S5. Individual bodily changes

From Supplementary Table 4 it is evident that no individual items are unique to any specific pain group, nor are there any that were not reported by any pain-free controls. Respondents with pain reported most bodily changes with greater frequency than respondents without pain, and respondents with CRPS and/or fibromyalgia reported most bodily changes with greater frequency than pain controls. Respondents with CRPS (with or without fibromyalgia) reported with greater frequency than the other groups those individual items that are part of the CRPS diagnostic criteria (e.g., 'swelling [oedema] in any body part'). However, respondents with fibromyalgia (without CRPS) also reported these items more frequently than the two control populations. Individual items that were reported with greater frequency by respondents with fibromyalgia (with or without CRPS) than the other groups include most items categorised under vision and hearing changes, 'increased susceptibility to illness', items related to bowel function ('loose bowels, diarrhoea, or needing to defecate more often', 'constipation'), 'allergic reactions to food and drink', and 'loss of sexual desire'. However, respondents with CRPS (without fibromyalgia) also reported these items more frequently than the two control populations. Individual items that were reported with greater frequency by the CRPS+fibromyalgia group than any other group included 'losing the hair on your head', 'finding your skin takes longer to heal when cut or bruised', 'falling more frequently', 'difficulties walking', and 'hay fever'.

The responses that were provided in the free-text box are depicted per category in Supplementary Figure 2.

Supplementary Table 4. Categorization of the predefined bodily changes that respondents could select as answer to the question: *'Have you experienced any of the following since the onset of your pain condition/over the past two years? Please only select those things that have started to bother you or have become worse since the onset of your pain condition/over the past two years. Select ANY that apply.'* Values are not corrected for covariates.

Bodily change	**CRPS (*N* = 390)**	**Fibromyalgia (*N* = 452)**	**CRPS+ Fibromyalgia (*N* = 88)**	**Pain controls (*N* = 311)**	**Pain-free controls (*N* = 441)**	**Statistics**
Vision and hearing changes						
Blurred vision	142 (36.4%)[2,3,4,5]	258 (57.1%)[1,4,5]	51 (58.0%)[1,4,5]	67 (21.5%)[1,2,3]	88 (20.0%)[1,2,3]	$\chi^2(4) = 183.04$, $p < .001$
Needing to change your glasses or contact lens prescription more often	94 (24.1%)[2,3,4,5]	172 (38.1%)[1,4,5]	35 (39.8%)[1,4,5]	47 (15.1%)[1,2,3]	75 (17.0%)[1,2,3]	$\chi^2(4) = 82.38$, $p < .001$
Peripheral vision loss	20 (5.1%)	30 (6.6%)[5]	6 (6.8%)	8 (2.6%)	7 (1.6%)[2]	$\chi^2(4) = 18.45$, $p = .001$
Sensitivity to bright lights	162 (41.5%)[2,3,4,5]	320 (70.8%)[1,4,5]	57 (64.8%)[1,4,5]	93 (29.9%)[1,2,3,5]	71 (16.1%)[1,2,3,4]	$\chi^2(4) = 313.15$, $p < .001$
Hearing loss	46 (11.8%)[2]	96 (21.2%)[1,4,5]	14 (15.9%)	23 (7.4%)[2]	31 (7.0%)[2]	$\chi^2(4) = 52.20$, $p < .001$
Tinnitus (Ringing in the ears)	109 (27.9%)[2,5]	214 (47.3%)[1,4,5]	34 (38.6%)[4,5]	68 (21.9%)[2,3,5]	43 (9.8%)[1,2,3,4]	$\chi^2(4) = 168.13$, $p < .001$
Sensitivity to loud noises	215 (55.1%)[2,3,4,5]	320 (70.8%)[1,4,5]	65 (73.9%)[1,4,5]	96 (30.9%)[1,2,3,5]	55 (12.5%)[1,2,3,4]	$\chi^2(4) = 381.42$, $p < .001$
Hair, skin, and nail changes						
Losing hair on your head	124 (31.8%)[3,4,5]	171 (37.8%)[3,4,5]	50 (56.8%)[1,2,4,5]	63 (20.3%)[1,2,3]	84 (19.0%)[1,2,3]	$\chi^2(4) = 83.96$, $p < .001$
Losing hair on parts of your body other than your head*	67 (17.2%)[4,5]	52 (11.5%)[3,4,5]	21 (23.9%)[2,4,5]	18 (5.8%)[1,2,3]	11 (2.5%)[1,2,3]	$\chi^2(4) = 75.68$, $p < .001$
Extra hair growth on any part of your body*	136 (34.9%)[2,4,5]	76 (16.8%)[1,3,4,5]	35 (39.8%)[2,4,5]	23 (7.4%)[1,2,3]	42 (9.5%)[1,2,3]	$\chi^2(4) = 145.29$, $p < .001$
Skin rashes	150 (38.5%)[4,5]	212 (46.9%)[4,5]	41 (46.6%)[4,5]	59 (19.0%)[1,2,3]	56 (12.7%)[1,2,3]	$\chi^2(4) = 164.25$, $p < .001$
Being more susceptible to sunburn	137 (35.1%)[2,4,5]	105 (23.2%)[1,3,4,5]	37 (42.0%)[2,4,5]	34 (10.9%)[1,2,3]	38 (8.6%)[1,2,3]	$\chi^2(4) = 132.13$, $p < .001$
Changes in the texture of your skin*	250 (64.1%)[2,4,5]	153 (33.8%)[1,3,4,5]	54 (61.4%)[2,4,5]	54 (17.4%)[1,2,3,5]	49 (11.1%)[1,2,3,4]	$\chi^2(4) = 331.21$, $p < .001$
Changes in skin colour*	300 (76.9%)[2,4,5]	55 (12.2%)[1,3,5]	58 (65.9%)[2,4,5]	22 (7.1%)[1,3]	16 (3.6%)[1,2,3]	$\chi^2(4) = 799.53$, $p < .001$
Swelling (oedema) in any body part*	321 (82.3%)[2,4,5]	186 (41.2%)[1,3,4,5]	73 (83.0%)[2,4,5]	79 (25.4%)[1,2,3,5]	24 (5.4%)[1,2,3,4]	$\chi^2(4) = 602.61$, $p < .001$
Changes in the nails of your hands (e.g., growing faster or slower, or being more brittle)*	207 (53.1%)[4,5]	219 (48.5%)[3,4,5]	57 (64.8%)[2,4,5]	58 (18.6%)[1,2,3,5]	50 (11.3%)[1,2,3,4]	$\chi^2(4) = 270.84$, $p < .001$
Changes in your toenails (e.g., growing faster or slower, or being more brittle)*	228 (58.5%)[2,4,5]	152 (33.6%)[3,4,5]	57 (64.8%)[1,2,4,5]	41 (13.2%)[1,2,3,5]	26 (5.9%)[1,2,3,4]	$\chi^2(4) = 368.09$, $p < .001$
Allergic reactions on the skin	105 (26.9%)	146 (32.3%)	34 (38.6%)	55 (17.7%)	45 (10.2%)	$\chi^2(4) = 83.62$, $p < .001$

Infection and healing changes						
Increased susceptibility to illness (for example, becoming more frequently ill, or taking longer to recover from illness)	184 (47.2%)[2,3,4,5]	279 (61.7%)[1,4,5]	60 (68.2%)[1,4,5]	106 (34.1%)[1,2,3,5]	60 (13.6%)[1,2,3,4]	$\chi^2(4) = 256.33$, $p < .001$
Finding your skin takes longer to heal when cut or bruised	226 (57.9%)[3,4,5]	248 (54.9%)[3,4,5]	66 (75.0%)[1,2,4,5]	92 (29.6%)[1,2,3,5]	51 (11.6%)[1,2,3,4]	$\chi^2(4) = 299.81$, $p < .001$
Urinary/intestinal function						
Needing to urinate more often, or finding it difficult from stopping yourself urinate when you 'need to go'	141 (36.2%)[2,3,5]	277 (61.3%)[1,4,5]	57 (64.8%)[1,4,5]	95 (30.5%)[2,3,5]	81 (18.4%)[1,2,3,4]	$\chi^2(4) = 209.01$, $p < .001$
Needing to urinate less often, or finding it difficult to urinate	59 (15.1%)[2,4,5]	34 (7.5%)[1,5]	12 (13.6%)[4,5]	15 (4.8%)[1,3]	9 (2.0%)[1,23]	$\chi^2(4) = 58.37$, $p < .001$
Loose bowels, diarrhoea, or needing to defecate more often	110 (28.2%)[2,3,5]	245 (54.2%)[1,4,5]	44 (50.0%)[1,4,5]	83 (26.7%)[2,3,5]	52 (11.8%)[1,2,3,4]	$\chi^2(4) = 205.7$, $p < .001$
Constipation	156 (40.0%)[2,4,5]	263 (58.2%)[1,4,5]	46 (52.3%)[4,5]	76 (24.4%)[1,2,3,5]	41 (9.3%)[1,2,3,4]	$\chi^2(4) = 267.25$, $p < .001$
Drinking and eating changes						
Having a 'sensitive stomach'	149 (38.2%)[2,5]	258 (57.1%)[1,4,5]	39 (44.3%)[5]	111 (35.7%)[5]	94 (21.3%)[1,2,3,4]	$\chi^2(4) = 122.94$, $p < .001$
Nausea	157 (40.3%)[2,3,4,5]	233 (51.5%)[1,4,5]	49 (55.7%)[1,4,5]	94 (30.2%)[1,2,3,5]	42 (9.5%)[1,2,3,4]	$\chi^2(4) = 206.41$, $p < .001$
Increase in weight	215 (55.1%)[2,4,5]	318 (70.4%)[1,4,5]	56 (63.6%)[4,5]	114 (36.7%)[1,2,3,5]	111 (25.2%)[1,2,3,4]	$\chi^2(4) = 214.94$, $p < .001$
Decrease in weight	77 (19.7%)[5]	57 (12.6%)	19 (21.6%)[5]	39 (12.5%)	36 (8.2%)[1,3]	$\chi^2(4) = 29.16$, $p < .001$
Allergic reactions to food and drink	53 (13.6%)[2,5]	116 (25.7%)[1,4,5]	20 (22.7%)[5]	39 (12.5%)[2,5]	20 (4.5%)[1,2,3,4]	$\chi^2(4) = 85.62$, $p < .001$
Decreased alcohol tolerance	78 (20.0%)[2]	163 (36.1%)[1,4,5]	20 (22.7%)	51 (16.4%)[2]	66 (15.0%)[2]	$\chi^2(4) = 70.13$, $p < .001$
Increased alcohol tolerance	16 (4.1%)	28 (6.2%)	9 (10.0%)	12 (3.9%)	28 (6.3%)	$\chi^2(4) = 7.85$, $p = .100$
Changes related to movement						
Weakness in any part of your body*	339 (86.9%)[4,5]	386 (85.4%)[4,5]	79 (89.8%)[4,5]	184 (59.2%)[1,2,3,5]	73 (16.6%)[1,2,3,4]	$\chi^2(4) = 630.75$, $p < .001$
Tremor in any part of your body*	215 (55.1%)[2,3,4,5]	199 (44.0%)[1,3,4,5]	62 (70.5%)[1,2,4,5]	65 (20.9%)[1,2,3,5]	22 (5.0%)[1,2,3,4]	$\chi^2(4) = 341.54$, $p < .001$
Problems with balance	271 (69.5%)[4,5]	343 (75.9%)[4,5]	64 (72.7%)[4,5]	136 (43.7%)[1,2,3,5]	32 (7.3%)[1,2,3,4]	$\chi^2(4) = 525.7$, $p < .001$
Falling more frequently	165 (42.3%)[3,4,5]	174 (38.5%)[3,4,5]	51 (58.0%)[1,2,4,5]	61 (19.6%)[1,2,3,5]	11 (2.5%)[1,2,3,4]	$\chi^2(4) = 259.44$, $p < .001$
Difficulties walking	279 (71.5%)[3,4,5]	314 (69.5%)[3,4,5]	75 (85.2%)[1,2,4,5]	126 (40.5%)[1,2,3,5]	15 (3.4%)[1,2,3,4]	$\chi^2(4) =$, $p < .001$
Changes in biological responses						
Sweating more*	261 (66.9%)[4,5]	279 (61.7%)[4,5]	63 (71.6%)[4,5]	90 (28.9%)[1,2,3,5]	76 (17.2%)[1,2,3,4]	$\chi^2(4) = 320.54$, $p < .001$
Sweating less*	14 (3.6%)	11 (2.4%)	4 (4.5%)	11 (3.5%)	7 (1.6%)	$\chi^2(4) = 5.11$, $p = .276$
Dizziness	200 (51.3%)[2,3,4,5]	308 (68.1%)[1,4,5]	62 (70.5%)[1,4,5]	116 (37.3%)[1,2,3,5]	47 (10.7%)[1,2,3,4]	$\chi^2(4) = 345.55$, $p < .001$

Hay fever	56 (14.4%)[3]	93 (20.6%)[3,4,5]	31 (35.2%)[1,2,4,5]	34 (10.9%)[2,3]	54 (12.2%)[2,3]	$\chi^2(4) = 42.74$, $p < .001$
Loss of sexual desire	202 (51.8%)[2,4,5]	281 (62.2%)[1,4,5]	56 (63.6%)[4,5]	113 (36.3%)[1,2,3,5]	57 (12.9%)[1,2,3,4]	$\chi^2(4) = 264.6$, $p < .001$
Increased sexual desire	9 (2.3%)[5]	9 (2.0%)[5]	1 (1.1%)	7 (2.3%)[5]	48 (10.9%)[1,2,4]	$\chi^2(4) = 60.03$, $p < .001$
Feeling unusually cold, or finding it difficult to get warm when you are cold	192 (49.2%)[2,4,5]	280 (61.9%)[1,4,5]	52 (59.1%)[4,5]	97 (31.2%)[1,2,3,5]	45 (10.2%)[1,2,3,4]	$\chi^2(4) = 292.00$, $p < .001$
Feeling unusually hot, or finding it difficult to cool down when you are hot	162 (41.5%)[2,3,4,5]	274 (60.6%)[1,4,5]	56 (63.6%)[1,4,5]	70 (22.5%)[1,2,3,5]	36 (8.2%)[1,2,3,4]	$\chi^2(4) = 327.83$, $p < .001$
One part or specific parts of your body feeling unusually cold*	252 (64.6%)[2,4,5]	145 (32.1%)[1,3,4,5]	48 (54.5%)[2,4,5]	58 (18.6%)[1,2,3,5]	38 (8.6%)[1,2,3,4]	$\chi^2(4) = 346.54$, $p < .001$
One part or specific parts of your body feeling unusually hot*	160 (41.0%)[2,4,5]	108 (23.9%)[1,3,4,5]	43 (48.9%)[2,4,5]	35 (11.3%)[1,2,3,5]	13 (2.9%)[1,2,3,4]	$\chi^2(4) = 239.19$, $p < .001$

* These items are part of the Budapest clinical diagnostic criteria for CRPS [1]

Group mean differed significantly from [1]CRPS, [2]Fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls.

S6. Individual pain/discomfort/distress triggers and pain intensifiers

From Supplementary Table 5 and Supplementary Figure 3 it is evident that there are no individual items that were uniquely reported by any one pain group. Nor are there any items that were not reported as triggering pain, discomfort, and distress for at least some pain-free controls, although the frequencies of these reports are lower than for the pain groups. Most items were reported by a higher proportion of respondents with CRPS and/or fibromyalgia compared to the pain control group.

Respondents with fibromyalgia reported more often that caffeine, alcohol, bright lights, flashing lights, high-contrast images, loud or unpleasant noises, particular foods and particular smells triggered pain, discomfort, or distress; or intensified pain compared to respondents with CRPS. Respondents with CRPS reported more often that the touch of clothing/water/breeze triggered pain and distress; and intensified pain compared to respondents with fibromyalgia. Respondents with CRPS+fibromyalgia reported loud or unpleasant noises and warm/hot weather to trigger and intensify pain more often compared to respondents with only one of these conditions.

The responses that were provided in the free-text box are depicted per category in Supplementary Figure 4. The number of respondents who spontaneously mentioned additional items in the free-text box was lower than 10% per group, limiting how meaningful even qualitative group comparisons can be.

Supplementary Table 5. Proportion of respondents that choose each of the individual pain, discomfort, and distress triggers; and pain intensifiers.

Sensory sensitivity	CRPS (*N* = 339)	Fibromyalgia (*N* = 403)	CRPS+ Fibromyalgia (*N* = 79)	Pain controls (*N* = 275)	Pain-free controls (*N* = 393)	Statistics
Pain triggers						
Caffeine	7 (2.1%)	23 (5.7%)[5]	5 (6.3%)	10 (3.6%)	6 (1.5%)[2]	$\chi^2(4) = 14.57$, $p = .006$
Alcohol	22 (6.5%)[2,5]	54 (13.4%)[1,4,5]	10 (12.7%)[5]	12 (4.4%)[2,5]	3 (0.8%)[1,2,3,4]	$\chi^2(4) = 57.33$, $p < .001$
Bright lights	56 (16.5%)[2.5]	119 (29.5%)[1,4,5]	15 (19.0%)[5]	29 (10.5%)[2,5]	11 (2.8%)[1,2,3,4]	$\chi^2(4) = 115.44$, $p < .001$
Flashing lights	59 (17.4%)[4,5]	94 (23.3%)[4,5]	12 (15.2%)[5]	22 (8.0%)[1,2,5]	7 (1.8%)[1,2,3,4]	$\chi^2(4) = 93.77$, $p < .001$
High-contrast images	15 (4.4%)	29 (7.2%)[5]	5 (6.3%)	11 (4.0%)	6 (1.5%)	$\chi^2(4) = 15.89$, $p = .003$
Loud or unpleasant noises	101 (29.8%)[3,4,5]	115 (28.5%)[3,4,5]	35 (44.3%)[1,2,4,5]	41 (14.9%)[1,2,3,5]	13 (3.3%)[1,2,3,4]	$\chi^2(4) = 138.03$, $p < .001$
The touch of clothing/water/breeze	238 (70.2%)[2,4,5]	116 (28.8%)[1,3,4,5]	56 (70.9%)[2,4,5]	31 (11.3%)[1,2,3,5]	4 (1.0%)[1,2,3,4]	$\chi^2(4) = 528.39$, $p < .001$
Particular foods	31 (9.1%)[2.5]	97 (24.1%)[1,4,5]	13 (16.5%)[5]	27 (9.8%)[2,5]	16 (4.1%)[1,2,3,4]	$\chi^2(4) = 82.05$, $p < .001$
Particular smells	17 (5.0%)[5]	32 (7.9%)[4,5]	10 (12.7%)[4,5]	4 (1.5%)[2,3]	3 (0.8%)[1,2,3]	$\chi^2(4) = 42.84$, $p < .001$
Cold weather	224 (66.1%)[4,5]	240 (59.6%)[3,4,5]	59 (74.7%)[2,4,5]	79 (28.7%)[1,2,3,5]	20 (5.1%)[1,2,3,4]	$\chi^2(4) = 406.56$, $p < .001$
Warm or hot weather	124 (36.6%)[2,3,4,5]	102 (25.3%)[1,3,4,5]	39 (49.4%)[1,2,4,5]	30 (10.9%)[1,2,3,5]	4 (1.0%)[1,2,3,4]	$\chi^2(4) = 209.98$, $p < .001$
Other	71 (20.9%)[4,5]	58 (14.4%)[5]	13 (16.5%)[5]	34 (12.4%)[1]	5 (1.3%)[1,2,3,4]	$\chi^2(4) = 71.38$, $p < .001$
Discomfort triggers						
Caffeine	30 (8.8%)	61 (15.1%)	9 (11.4%)	27 (9.8%)	42 (10.7%)	$\chi^2(4) = 8.66$, $p = .070$
Alcohol	41 (12.1%)[2]	82 (20.3%)[1]	10 (12.7%)	34 (12.4%)	66 (16.8%)	$\chi^2(4) = 13.16$, $p = .011$
Bright lights	156 (46.0%)[2,5]	286 (71.0%)[1,4,5]	45 (57.0%)[4,5]	108 (39.3%)[2,3]	140 (35.6%)[1,2,3]	$\chi^2(4) = 119.48$, $p < .001$
Flashing lights	131 (38.6%)[2]	240 (59.6%)[1,4,5]	41 (51.9%)[4,5]	84 (30.5%)[2,3]	119 (30.3%)[2,3]	$\chi^2(4) = 92.84$, $p < .001$
High-contrast images	98 (28.9%)[2,3,5]	198 (49.1%)[1,4,5]	37 (46.8%)[1,4,5]	60 (21.8%)[2,3]	76 (19.3%)[1,2,3]	$\chi^2(4) = 106.62$, $p < .001$
Loud or unpleasant noises	153 (45.1%)[2,5]	239 (59.3%)[1,4,5]	44 (55.7%)[4,5]	97 (35.3%)[2,3]	137 (34.9%)[1,2,3]	$\chi^2(4) = 63.82$, $p < .001$
The touch of clothing/water/breeze	144 (42.5%)[4,5]	202 (50.1%)[4,5]	32 (40.5%)[4,5]	43 (15.6%)[1,2,3,5]	25 (6.4%)[1,2,3,4]	$\chi^2(4) = 238.81$, $p < .001$
Particular foods	38 (11.2%)[2,3]	106 (26.3%)[1,4,5]	19 (24.1%)[1]	35 (12.7%)[2]	55 (14.0%)[2]	$\chi^2(4) = 41.65$, $p < .001$
Particular smells	26 (7.7%)[2,3]	109 (27.0%)[1,4,5]	16 (20.3%)[1,5]	27 (9.8%)[2]	24 (6.1%)[2,3]	$\chi^2(4) = 97.47$, $p < .001$
Cold weather	106 (31.3%)[5]	160 (39.7%)[4,5]	28 (35.4%)[5]	74 (26.9%)[2,5]	39 (9.9%)[1,2,3,4]	$\chi^2(4) = 96.30$, $p < .001$
Warm or hot weather	97 (28.6%)[2,4,5]	157 (39.0%)[1,4,5]	29 (36.7%)[4,5]	47 (17.1%)[1,2,3]	46 (11.7%)[1,2,3]	$\chi^2(4) = 95.55$, $p < .001$
Other	40 (11.8%)[5]	53 (13.2%)[5]	7 (8.9%)[5]	22 (8.0%)[5]	8 (2.0%)[1,2,3,4]	$\chi^2(4) = 36.18$, $p < .001$
Distress triggers						
Caffeine	5 (1.5%)[2]	26 (6.5%)[1]	3 (3.8%)	13 (4.7%)	18 (4.6%)	$\chi^2(4) = 11.18$, $p = .025$

Alcohol	20 (5.9%)	21 (5.2%)	6 (7.6%)	19 (6.9%)	21 (5.3%)	$\chi^2(4) = 1.48$, $p = .830$
Bright lights	54 (15.9%)[2,5]	98 (24.3%)[1,4,5]	10 (12.7%)[5]	34 (12.4%)[2,5]	15 (3.8%)[1,2,3,4]	$\chi^2(4) = 70.50$, $p < .001$
Flashing lights	58 (17.1%)[1,5]	111 (27.5%)[2,4,5]	19 (24.1%)[5]	40 (14.5%)[2,5]	23 (5.9%)[1,2,3,4]	$\chi^2(4) = 70.78$, $p < .001$
High-contrast images	24 (7.1%)[2]	69 (17.1%)[1,4,5]	9 (11.4%)	16 (5.8%)[2]	15 (3.8%)[2]	$\chi^2(4) = 51.17$, $p < .001$
Loud or unpleasant noises	89 (26.3%)[2,5]	164 (40.7%)[1,4,5]	30 (38.0%)[4,5]	55 (20.0%)[2,3,5]	45 (11.5%)[1,2,3,4]	$\chi^2(4) = 100.15$, $p < .001$
The touch of clothing/water/breeze	78 (23.0%)[2,4,5]	52 (12.9%)[1,4,5]	17 (21.5%)[4,5]	16 (5.8%)[1,2,3]	10 (2.5%)[1,2,3]	$\chi^2(4) = 91.54$, $p < .001$
Particular foods	19 (5.6%)	45 (11.2%)[5]	6 (7.6%)	14 (5.1%)	10 (2.5%)[2]	$\chi^2(4) = 26.69$, $p < .001$
Particular smells	20 (5.9%)[2,5]	62 (15.4%)[1,4,5]	11 (13.9%)[4,5]	13 (4.7%)[2,3]	7 (1.8%)[1,2,3]	$\chi^2(4) = 62.94$, $p < .001$
Cold weather	69 (20.4%)[4,5]	77 (19.1%)[4,5]	17 (21.5%)[4,5]	27 (9.8%)[1,2,3,5]	7 (1.8%)[1,2,3,4]	$\chi^2(4) = 79.50$, $p < .001$
Warm or hot weather	59 (17.4%)[4,5]	75 (18.6%)[4,5]	21 (26.6%)[4,5]	18 (6.5%)[1,2,3]	12 (3.1%)[1,2,3]	$\chi^2(4) = 76.91$, $p < .001$
Other	30 (8.8%)[5]	47 (11.7%)[5]	7 (8.9%)[5]	15 (5.5%)	7 (1.8%)[1,2,3]	$\chi^2(4) = 32.57$, $p < .001$
Pain intensifiers						
Caffeine	21 (6.2%)	44 (10.9%)	7 (8.9%)	27 (9.8%)		$\chi^2(3) = 5.28$, $p = .153$
Alcohol	34 (10.0%)	66 (16.4%)	10 (12.7%)	27 (9.8%)		$\chi^2(3) = 9.24$, $p = .026$
Bright lights	122 (36.0%)[2,4]	218 (54.1%)[1,4]	38 (48.1%)[4]	73 (26.5%)[1,2,3]		$\chi^2(3) = 57.41$, $p < .001$
Flashing lights	100 (29.5%)[2,4]	170 (42.2%)[1,4]	30 (38.0%)[4]	53 (19.3%)[1,2,3]		$\chi^2(3) = 41.78$, $p < .001$
High-contrast images	47 (13.9%)[2]	93 (23.1%)[1,4]	20 (25.3%)[4]	24 (8.7%)[2,3]		$\chi^2(3) = 30.39$, $p < .001$
Loud or unpleasant noises	178 (52.5%)[3,4]	229 (56.8%)[3,4]	57 (72.2%)[1,2,4]	87 (31.6%)[1,2,3]		$\chi^2(3) = 60.93$, $p < .001$
The touch of clothing/water/breeze	267 (78.8%)[2,4]	175 (43.4%)[1,3,4]	62 (78.5%)[2,4]	44 (16.0%)[1,2,3]		$\chi^2(3) = 271.93$, $p < .001$
Particular foods	31 (9.1%)[2]	68 (16.9%)[1,4]	11 (13.9%)	26 (9.5%)[2]		$\chi^2(3) = 13.09$, $p = .004$
Particular smells	18 (5.3%)[2]	74 (18.4%)[1,4]	11 (13.9%)	16 (5.8%)[2]		$\chi^2(3) = 42.21$, $p < .001$
Cold weather	221 (65.2%)[4]	228 (56.6%)[4]	53 (67.1%)[4]	94 (34.2%)[1,2,3]		$\chi^2(3) = 67.12$, $p < .001$
Warm or hot weather	155 (45.7%)[2,4]	134 (33.3%)[1,3,4]	43 (54.4%)[2,4]	40 (14.5%)[1,2,3]		$\chi^2(3) = 82.01$, $p = .001$
Other	54 (15.9%)	56 (13.9%)	13 (16.5%)	40 (14.5%)		$\chi^2(3) = 0.78$, $p = .854$

Group mean differed significantly from [1]CRPS, [2]Fibromyalgia, [3]CRPS+fibromyalgia, [4]pain controls, and [5]pain-free controls.

S7. Predictors of somatic sensations, bodily changes and sensory sensitivity

Supplementary Table 6. Outcomes of the multiple regression model of somatic sensations, bodily changes, pain/discomfort/distress triggers and pain intensifiers for respondents with CRPS and fibromyalgia.

	CRPS			**Fibromyalgia**		
Dependent / independent variables	***F* / B (95% CI)**	***p***	***R*²**	***F* / B (95% CI)**	***p***	***R*²**
Somatic sensations (PHQ-15)	*F*(7) = 28.07	< .001	.39	*F*(7) = 34.74	< .001	.41
Gender	0.90 (-0.45 to 2.25)	.190	.01	-0.07 (-1.77 to 1.62)	.931	0
Age	-0.02 (-0.05 to 0.02)	.422	0	-0.03 (-0.06 to 0)	.069	0.01
PHQ-9	0.25 (0.14 to 0.37)	< .001*	.06	0.29 (0.19 to 0.39)	< .001*	0.09
GAD-7	0.22 (0.10 to 0.34)	< .001*	.04	0.19 (0.10 to 0.29)	< .001*	0.04
Pain duration in years	0.05 (-0.01 to 0.11)	.076	.01	-0.02 (-0.06 to 0.02)	.431	0
Hours of pain per day	0.04 (-0.03 to 0.11)	.222	0	0.05 (-0.01 to 0.10)	.111	0.01
Number of medical diagnoses	0.57 (0.29 to 0.85)	< .001*	.05	0.30 (0.09 to 0.50)	.005*	0.02
Total number of bodily changes	*F*(7) = 15.00	< .001	.26	*F*(7) = 25.20	< .001	.34
Gender	0.89 (-1.41 to 3.19)	.446	0	2.58 (-0.48 to 5.64)	.098	.01
Age	0.03 (-0.03 to 0.09)	.362	0	0.02 (-0.04 to 0.08)	.530	0
PHQ-9	0.31 (0.12 to 0.51)	.002*	.03	0.43 (0.25 to 0.60)	< .001*	.01
GAD-7	0.11 (-0.09 to 0.31)	.284	0	0.07 (-0.11 to 0.24)	.446	0
Pain duration in years	0.09 (-0.01 to 0.18)	.078	.01	0.10 (0.03 to 0.17)	.009*	.01
Hours of pain per day	0.16 (0.04 to 0.27)	.007*	.02	0.12 (0.02 to 0.23)	.019*	.02
Number of medical diagnoses	1.33 (0.86 to 1.81)	< .001*	.09	0.95 (0.58 to 1.32)	< .001*	.03
Proportion of pain/discomfort/distress triggers	*F*(7) = 7.24	< .001	.14	*F*(7) = 9.03	< .001	.15
Gender	0.44 (-0.13 to 1.01)	.126	.01	0.66 (-0.27 to 1.62)	.160	.01
Age	0 (-0.02 to 0.01)	.652	0	-0.01 (-0.03 to 0.01)	.205	0
PHQ-9	0.04 (-0.01 to 0.09)	.124	.01	0.05 (-0.01 to 0.10)	.081	.01
GAD-7	0.05 (0 to 0.10)	.062	.01	0.02 (-0.03 to 0.08)	.377	0
Pain duration in years	0.02 (0 to 0.04)	.106	.01	0.02 (0 to 0.04)	.059	.01
Hours of pain per day	0.02 (-0.01 to 0.04)	.301	0	0.04 (0.01 to 0.07)	.020*	.02
Number of medical diagnoses	0.20 (0.08 to 0.32)	.001*	.04	0.19 (0.08 to 0.31)	.001*	.03
Pain intensifiers	*F*(7) = 5.39	< .001	.11	*F*(7) = 6.25	< .001	.11
Gender	0.37 (-0.43 to 1.17)	.364	0	0.97 (-0.29 to 2.22)	.129	.01
Age	0.01 (-0.01 to 0.04)	.227	0	0 (-0.03 to 0.02)	.729	0
PHQ-9	0.04 (-0.03 to 0.11)	.227	0	0.07 (0 to 0.15)	.046*	.01

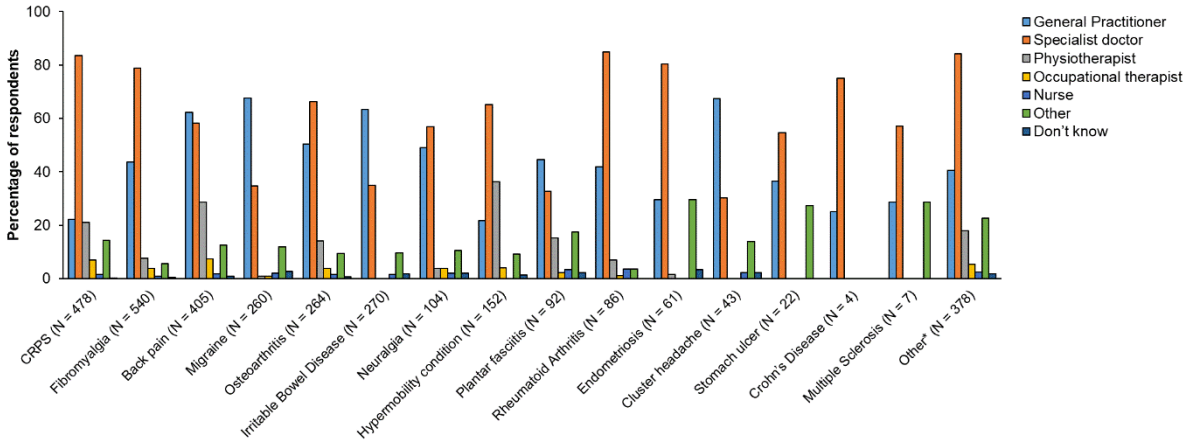
GAD-7	0.04 (-0.03 to 0.11)	.305	0	-0.05 (-0.12 to 0.02)	.197	0
Pain duration in years	0.04 (0.01 to 0.08)	.008*	.02	0.06 (0.03 to 0.09)	< .001*	.04
Hours of pain per day	0.03 (-0.01 to 0.07)	.091	.01	0.02 (-0.02 to 0.07)	.280	0
Number of medical diagnoses	0.23 (0.07 to 0.40)	.006*	.02	0.13 (-0.03 to 0.28)	.105	.01

Abbreviations: Patient Health Questionnaire-9, PHQ-9; Patient Health Questionnaire-15, PHQ-15; Generalized Anxiety Disorder-7, GAD-7.

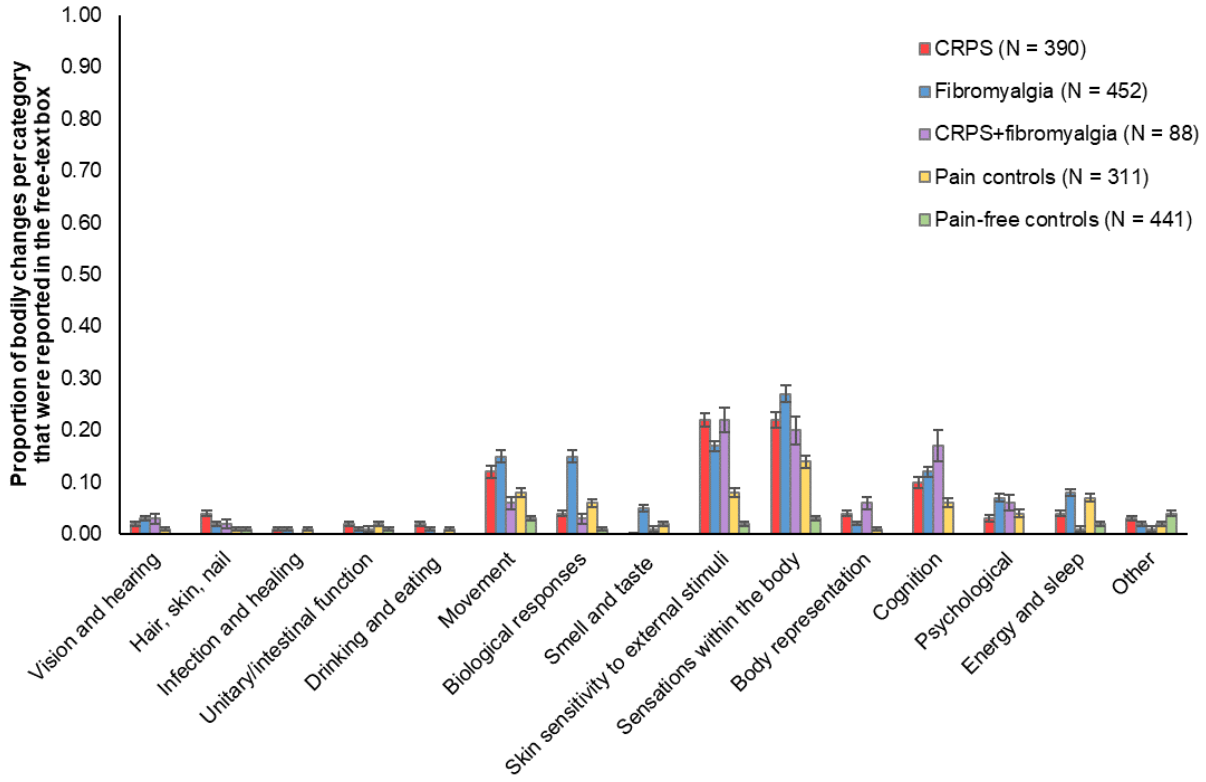
* Significant at alpha < .05

References

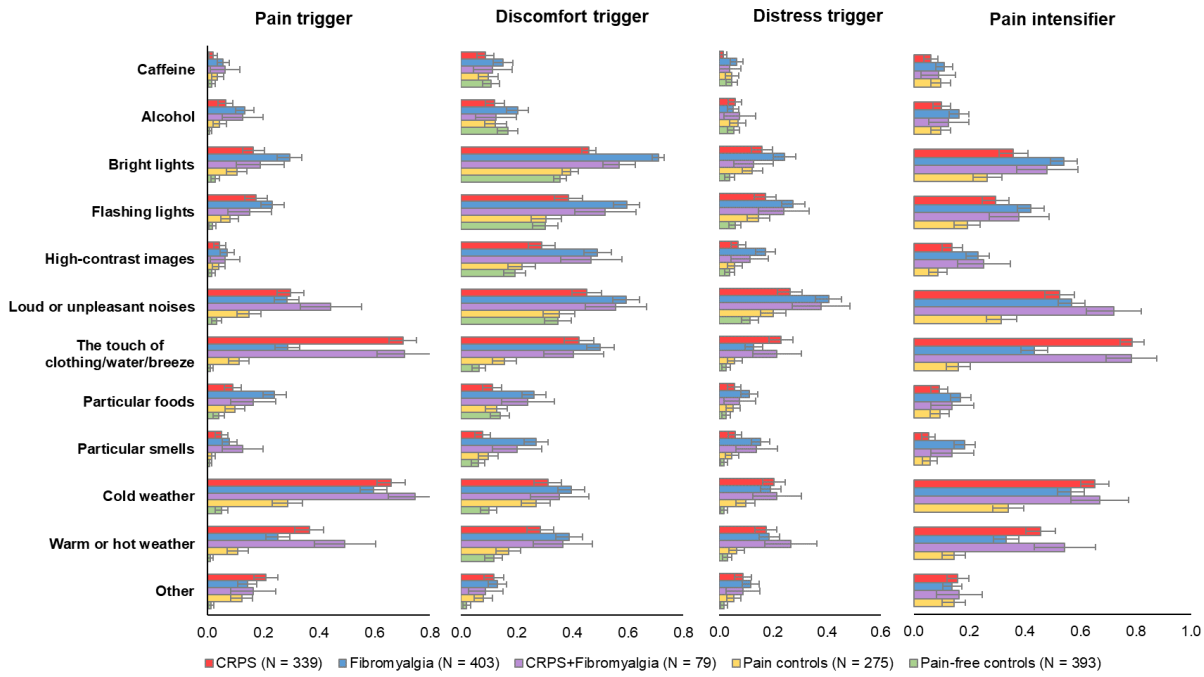
[1] Harden NR, Bruehl S, Perez RSGM, Birklein F, Marinus J, Maihofner C, Lubenow T, Buvanendran A, Mackey S, Graciosa J, Mogilevski M, Ramsden C, Chont M, Vatine J-J. Validation of proposed diagnostic criteria (the "Budapest Criteria") for Complex Regional Pain Syndrome. Pain 2010;150:268–274.



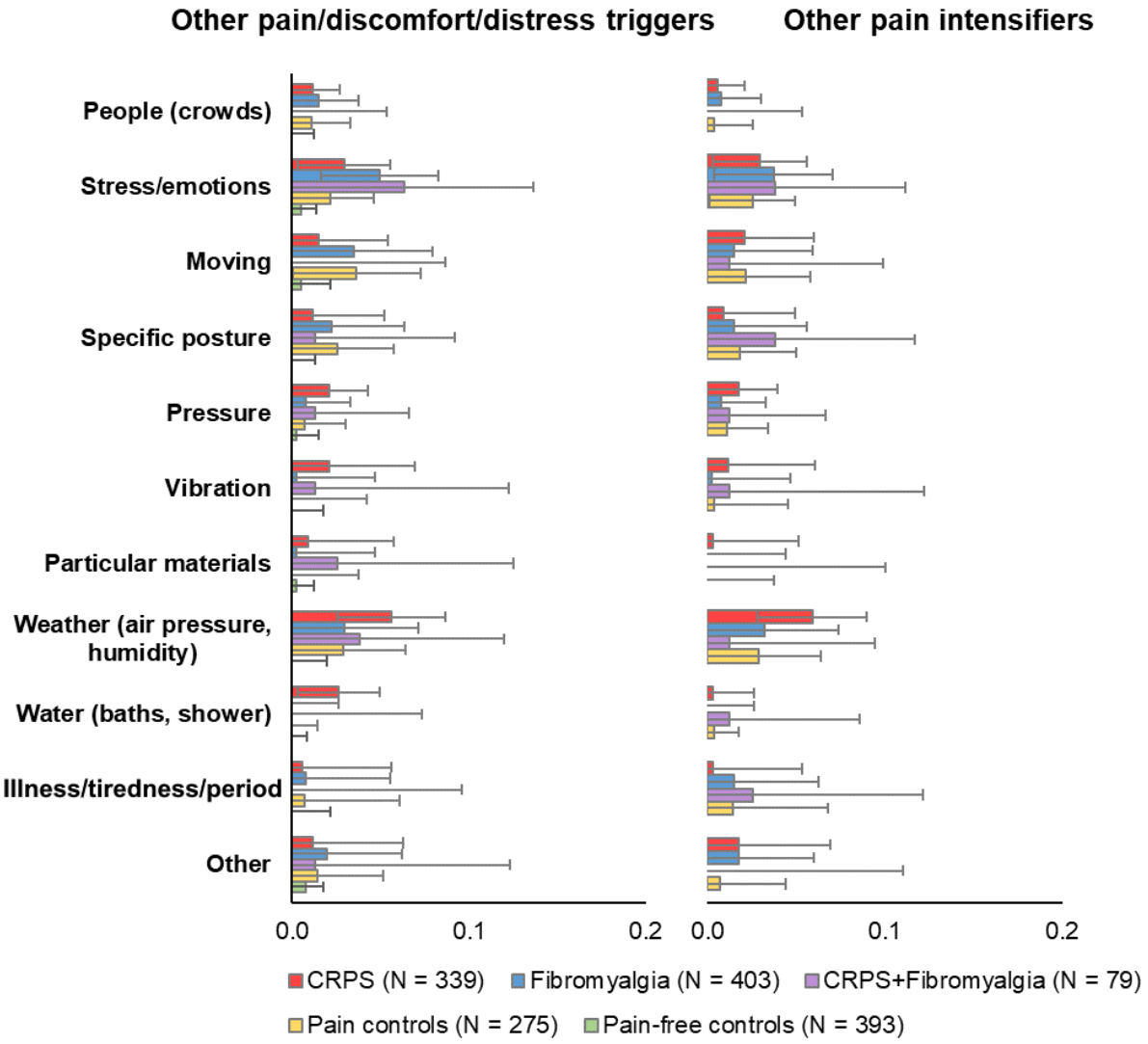
Supplementary Figure 1. Percentages of medical practitioners that respondents received their medical diagnosis from, split per medical diagnosis. Note that respondents could report multiple practitioners who had provided the medical diagnosis, thus percentages do not sum to 100. * 'Other' medical diagnoses indicate the number of respondents who received 1 or more other medical diagnosis



Supplementary Figure 2. Proportion of bodily changes provided in the free-text box, depicted per category. Answers in the free-text box were categorized in the existing categories or in new categories. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.



Supplementary Figure 3. Proportion of respondents who selected each of the pain, discomfort, distress triggers, and pain intensifiers. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.



Supplementary Figure 4. Proportion of pain/discomfort/distress triggers provided in the free-text box, depicted per category. Answers in the free-text box were categorized in the existing categories or in new categories. Error bars depict 95% confidence intervals. Note that these means are not corrected for our covariates, nor did we compare groups statistically.