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Pain location and widespread pain in youth with orthopedic conditions: Exploration of the reliability and validity of a body map

Running Head: Reliability and validity of a pediatric body map

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Significance: These results contribute to the limited available information regarding psychometric properties of pediatric pain body maps, and provide novel information about widespread pain among children undergoing orthopedic surgeries.

Introduction

Pain in youth is often difficult to assess, quantify, and monitor over time due to the multifaceted nature of pain and potential limits in children's and adolescents' self-report skills. Important components of pain assessment include intensity, duration or frequency, and pain location. Localization of pain is particularly crucial for appropriate diagnosis and to help guide appropriate interventions. Body maps have been developed so that individuals can identify the location of their pain, aid with appropriate diagnoses, enable empiric, standardized documentation, and facilitate determination of whether pain has spread. In addition to localizing pain, assessing the degree to which pain has become widespread is particularly important since multi-site pain has been associated with more severe daily functional impairment and lower quality of life in children and adults with chronic pain, and is considered a distinct clinical phenotype of pediatric chronic pain (Brummett et al. 2016; Rabbitts, Holley, Groenewald, & Palermo, 2016; Zempsky et al. 2017). Given the importance of differentiating localized pain from widespread pain in children and adolescents, it is important to better understand the ability of youth to reliably report pain location and spread, especially among populations at risk for developing chronic pain (Rabbitts & Fischer, 2017; Sieberg et al. 2013; Voepel-Lewis et al., 2017).

It is also important to understand how youths' reported pain locations relate to other dimensions of pain and outcomes, yet minimal data on small samples have been published about the reliability and validity of body maps (Hamill, Lyndon , Liley , & Hill, 2014). Children's body map markings agreed with their pointing to pain location between 83 and 94% of assessments, supporting the concurrent validity of these tools. Additionally, children's pain site markings were between 74 and 100% concordant with investigator observation or expected pain sites based on medical record diagnosis (Zempsky et al., 2017). Lastly, more widespread pain as identified by body map scores was associated with more functional impairment and lower health-related quality of life scores (Rabbitts et al., 2016). Despite the limited and variable data regarding body map reliability and associative validity in children, their use is considered to be important for clinical pain research (McGrath et al., 2008; Rabbitts et al., 2016).

Recently, the SUPER-KIDZ body map was developed from consensus data from a group of pediatric pain and rheumatology experts (Stinson et al., 2009). A primary advantage of this map is the ability to identify specific locations and to classify regional pain and widespread pain. Although preliminary evidence suggests 2-week stability in pain location identified by children with scoliosis (Voepel-Lewis et al., 2017), further exploration of reliability and validity of this body map is needed (von Baeyer, Lin, Seidman, Tsao, & Zeltzer, 2011).

The overall aim of this prospective, exploratory study was to assess the consistency, descriptive validity, and associative validity of body map reports in a sample of children and adolescents with underlying orthopedic conditions and who are at risk for developing chronic pain. Specifically, we aimed to examine:

1) The *discrepancy* with which youth with orthopedic conditions report pain locations from preoperative clinic visit (baseline assessment) to day of surgery (second assessment) approximately two weeks later (proxy for *test-retest reliability*),
2) The degree to which youth identified pain locations agree with the underlying diagnostic site (*descriptive validity*), and

3) The degree to which total body map scores and widespread pain correlate with concurrent measures of pain intensity, pain interference, and other self-reported outcomes (*associative validity*).

Specific hypotheses included:

1) Youth will report locations from preoperative clinic visit to day of surgery with low discrepancy,
2) Pain locations endorsed on the body map will be associated with the area of underlying diagnostic site, and
3) Total body map scores and widespread pain will correlate with concurrent measures of pain and other self-reported outcomes.

Method

Participants

With IRB approval, parental informed consent and child assent, one hundred thirty-two youth aged 10 to 17 years were consecutively recruited for a larger, ongoing study of pain in children with orthopedic conditions at an academic medical center in the Midwest. Included were English-speaking children scheduled to undergo elective surgical correction for an orthopedic condition between July 2014 through December 2016. We excluded youths with significant cognitive impairment who could not self-report pain or complete surveys independently, and those undergoing a secondary or repeated major orthopedic procedure. Additionally, we excluded youth with severe comorbidities, and only included those classified as healthy patients in ASA class 1-2 according to anesthesia pre-operative testing guidelines.

Measures

Youth used the 0-10 numeric rating scale (NRS) to rate their worst pain intensity over the recent 6 months and their worst pain in the past week (Castarlenas, Jensen, von Baeyer, & Miró, 2017).

Youths used the two-sided (front and back) SUPER-KIDZ body map to identify the location of their pain as this tool has face validity and is recommended for unassisted use in children as young as 8 years of age (see Figure 2, Stinson et al. 2009; von Baeyer et al. 2011). Youth were instructed to mark all parts of the body where they recalled pain in the recent 6 months. They circled areas with the most pain and shaded all areas where pain was present during the past week. A trained research assistant was present with the child during these instructions and completion of these tasks. Youth who indicated no recent pain ticked a box at the bottom of the body map. Two variables were created from data on the body map. First, the total number of pain sites endorsed on the body map was summed to create a total body map score. For the purpose of this study, the body sites ranged from 0-23 (i.e., Head, Jaw (R, L), Shoulder (R, L), Arm or Leg (R, L, Upper, Lower), Knee (R, L), Chest, Abdomen, Neck, Back (Upper, Middle, Lower). Second, in order to create a widespread pain score we first coded the child's identified pain regions as: Left side of the body, right side of the body, above the waist (head, jaw, neck, arms, shoulders, upper back, middle back, chest, abdomen), below the waist (hips, low back, legs), and axial pain in the chest or back. These pain regions were then coded into a widespreadedness ordinal variable where 1 = 2 or fewer pain regions, 2 = 3 regions, 3 = 4 regions, and 4 = 5 regions (Rabbitts et al., 2016).

Youth also completed the painDETECT which is a 9-item survey modified slightly to reduce the reading level and improve its relevance to children/adolescents. This instrument has been shown to differentiate neuropathic from nociceptive pain in adults and a recent study demonstrated high internal consistency (Cronbach α = 0.757 [95% CI 0.662, 0.834]) and test-retest reliability (ICC = 0.654 [95% CI 0.365, 0.811]) in scores in children aged 8-17 years (Voepel-Lewis et al., 2017).

Youth also completed the Pediatric Patient-Reported Outcome Measurement System (PROMIS) Short Forms for pain interference, fatigue, depression, and anxiety at the baseline survey (Varni et al., 2011; Varni et al., 2014). These surveys were developed by the National Institutes of Health and have been found to have internal consistency and reliability among children as young as 8 years old for self-report measures (Forrest, Bevans, Tucker, Riley, Ravens-Sieberer, Gardner, & Pajer, 2012). Lastly, children completed the Pain Catastrophizing

Scale which is a 13-item questionnaire that assesses an exaggerated negative pain mental set in children ages 9-15 years. This instrument has excellent reliability and predictive validity for chronic pain disability (Vervoort, Goubert, Eccleston, Bijttebier, & Crombez, 2006).

The following data were also recorded at baseline: demographics including age, sex, race, and orthopedic condition. The orthopedic condition was coded by trained research assistants as chronic or acute, and according to location (upper back, mid to lower back, lower back, right or left upper extremity, and right or left lower extremity).

Procedure

Youth were recruited in the orthopedic clinic at the time of the preoperative visit or on the day of surgery if no preoperative clinic visit was scheduled. Whenever possible, youth were recruited at their pre-operative clinic visit to complete surveys. Once consented, youth were asked to complete several baseline assessments that included identification of pain presence, duration of pain, and identification of pain location.

To examine youths' consistency in identifying pain location, participants who completed baseline measures at a preoperative clinic visit were re-surveyed approximately 2 weeks later on the morning of surgery (second assessment). Some participants who did not attend a preoperative clinic visit completed one survey on the morning of surgery, so these were considered baseline assessments.

Statistical Analyses

All analyses were conducted using SPSS statistical software (v. 24, IBM, New York). Data were summarized using descriptive statistics and n (%) or means, standard deviations, and medians with percentiles, where applicable. Percent agreement and Kappa statistics were used to examine the discrepancy of children's pain location reports between baseline and second assessments (McHugh, 2012). Descriptive and associative validity were assessed using correlation coefficients (Spearman's rho). To assess associations between patient factors and the child's widespread pain reporting discrepancy, a discrepancy variable was calculated as the *absolute difference* between body map total score on the day of surgery (i.e., the second assessment) and the body map total score at the preoperative clinic visit (baseline assessment), with larger values indicating greater discrepancy between the body map total scores, and smaller values indicating lower discrepancy, or greater consistency, between the body map total scores. We also examined whether youth factors, such as age, moderated the degree of discrepancy between reports of pain location(s) using Spearman's rho correlation coefficients.

Power analysis. Post hoc power analysis were conducted with G-Power (v. 3.1, Faul, Erdfelder, Lang, & Buchner, 2007; Faul, Erdfelder, Buchner, & Lang, 2009). The post hoc power analysis revealed that with 130 participants, the sample was sufficiently powered to detect medium effect sizes for correlations ($\rho = .3$), with $1 - \beta = .95$.

Results

One hundred and thirty-four children and adolescents completed baseline assessments and 84 completed both the baseline and second assessments. Data from four participants were excluded due to either incomplete body map data (n=2) or the time to re-test was greater than 30 days (n=2). For youths who completed second assessments, the average time to completion of the 2nd survey was 14.2 ± 7.26 days. Youth who completed both surveys were similar in characteristics with a few differences. All youth who completed both surveys had chronic conditions. In comparison to children who only completed one survey, youths who completed both surveys were more likely to be female ($\chi^2 = 16.92$, $p < .001$), African American ($\chi^2 = 10.92$, $p = .01$), to have mid to low back pain or mid to upper back pain, and less upper extremity or lower extremity pain ($\chi^2 = 48.73$, $p < .001$), and to have had longer pain duration (1-3 months vs 1 month, $t(125) = -2.93$, $p = .004$). The overall sample is described in Table 1.

The majority of participants reported pain at baseline which included 92% of those with a back condition, 76% of those with a lower extremity condition, and 100% with an upper extremity condition. The distribution of total body map scores is presented in Figure 1.

Discrepancy. The degree of discrepancy between baseline and second assessment total body map scores ranged from 0-22; however, most youth (91.7%) had a small difference in scores between baseline and day of surgery (0-2 body site difference). Paired samples correlation coefficients demonstrate a significant relationship between participants' total body map score at baseline and at day of surgery, $r_s = .69$, $p < .001$. Kappa statistics and percent agreement for each body site are reported in Table 2.

Descriptive validity. Of the 100 patients who had a back diagnosis, 85% checked pain in an area on their back on the pain body map. Most participants who had a lower extremity diagnosis endorsed pain in the lower extremity on the body map ($n = 16$, 76%). Importantly, 4 patients (19%) with a lower extremity condition also identified back pain, 19% with a back condition and 33% with an upper extremity condition also endorsed lower extremity pain.

Associative validity. Baseline total body map scores were positively correlated with other qualities of pain, including pain intensity at baseline ($r_s = .50$, $p < .001$), duration of pain, ($r_s = .33$, $p < .001$), highest pain in the past 6 months ($r_s = .44$, $p < .001$), past week pain ($r_s = .55$, $p < .001$), and neuropathic pain ($r_s = .40$, $p < .001$). Baseline body map total scores were also positively correlated with self-report measures of pain catastrophizing ($r_s = .34$, $p < .001$), PROMIS fatigue ($r_s = .39$, $p < .001$), pain interference ($r_s = .40$, $p < .001$), functioning ($r_s = .22$, $p = .02$), and depressive symptoms ($r_s = .37$, $p < .001$). There were no significant differences in baseline total body map scores between children who had acute or chronic pain, $t(128) = -0.79$, $p = .43$.

Widespread pain at baseline was positively correlated with other qualities of pain, including highest pain in the past 6 months ($r_s = .19$, $p = .04$), past week pain ($r_s = .37$, $p < .001$), and neuropathic pain ($r_s = .24$, $p = .01$). Widespread pain at baseline was also positively correlated with catastrophizing ($r_s = .22$, $p = .04$), fatigue ($r_s = .24$, $p = .02$), pain interference ($r_s = .22$, $p = .02$), and depressive symptoms ($r_s = .24$, $p = .045$). Widespread pain was not significantly associated with duration of pain ($r_s = .05$, $p = .60$), nor pain intensity at baseline ($r_s = -.09$, $p =$

.34). There was no significant differences in widespread pain between children who had acute or chronic pain, $t(113) = -1.66$, $p = .10$.

Associations between patient factors and discrepancy. Ratings of highest pain intensity in the past week at baseline was positively correlated with degree of discrepancy between the two body map scores, suggesting that higher pain intensity predicted greater discrepancy. Additionally, widespread pain at baseline was positively associated between the degree of discrepancy between the two body map scores, suggesting that the more widespread the pain, the more discrepant the two body map scores were (see Table 3).

Discussion

The results from this study suggest that the two-sided body map can be used with consistency by youth aged 10-17 years and may be useful to identify both localization of pain and widespread pain in children with orthopedic conditions who may be at risk for developing chronic pain. Low discrepancies between their baseline and day of surgery assessments support the reliability of this measure. The body map measure revealed baseline pain at the site of diagnoses in a large majority of youth with these conditions, supporting the descriptive validity of the measure. Importantly, though, many youth with orthopedic conditions indicated pain at sites farther from the area of injury or deformity, and nearly 1/3 of youth had high pain widespreadedness (4-5 regions). Given that widespread pain was associated with other measures including pain interference with function and catastrophizing, and has been associated with poorer long-term outcomes after surgery (Rabbitts et al. 2016), these findings suggest the importance of assessing for pain spread and regionalization. These findings have important implications, not only for research, but for reliable diagnoses and treatment of children in pain.

These results regarding relatively low body map discrepancy are promising because they suggest that children and adolescents can reliably report pain location over short periods of time. Importantly, discrepancy here was considered a proxy for test-retest reliability since pain locations can be expected to change, even over short periods (Savedra, Tesler, Holzemer, Wilkie, & Ward, 1989). As opposed to measures of trait constructs in which scores remain static, as state constructs, qualities of pain are considered to be more variable. While we expected some degree of consistency between pain location indicated on the body map, we also expected a degree of discrepancy or fluctuation because pain can move and change. In this study, total body map score discrepancy was low, suggesting excellent consistency among children with surgically correctable orthopedic diagnoses. The percent agreement between each body site was variable but high, ranging from 78% to 98%. Of interest was the finding that higher pain intensity was associated with discrepancy in total body map score reports. Additionally, widespread pain correlated positively with the youth's discrepancy. These findings suggest, perhaps, a higher degree of fluctuation in pain intensity and number of sites as pain spreads. The youths' painDETECT responses regarding pain spread and nature of the pain help to explain this finding. For instance, 40% of the sample described their pain as present "all the time but goes up and down" while 20% described "pain attacks without pain between them".

The degree of agreement between body map pain location and diagnostic site suggests that this measure is a valid indicator of pain location in children and an example of descriptive validity. Notably, not all children endorsed pain although they had diagnosed musculoskeletal defect. Given variability in pain reporting, correspondence with diagnostic site is therefore only a proxy for but not true criterion validity. A standard criterion measure for pain localization has not yet been determined to assess criterion validity for pain body maps, but perhaps initial and further steps toward validation of these measures will establish such a criterion in the field of pain assessment.

As expected, body map total scores and widespread pain were moderately positively related to other measures and symptoms including pain intensity, neuropathic pain quality, catastrophizing, fatigue, pain interference, and depression (associative validity). These results suggest that more widespread pain was associated with higher, or worse, self-reported symptoms. Importantly, multiple symptomology has been described in children with various chronic pain conditions and are highly important for chronic pain management (Eccleston, Crombez, Scotford, Clinch, & Connell, 2004; Gauntlett-Gilbert & Eccleston, 2007). These findings, similar to those of Rabbitts et al. 2016, highlight the importance of better assessing pain location.

Our findings regarding reliability and validity of this body map's utility among children undergoing orthopedic surgeries adds to the scant literature on the psychometric properties of pediatric pain body maps. Most body maps are understood to possess face validity. A body map that was modeled after the McGill Pain Questionnaire is currently in use in research (Rabbitts et al., 2016), but its known validity is limited to *alternate forms reliability* (i.e. children's pointing), and concurrent validity with investigator observation or medical record (Savedra et al., 1989). The Adolescent Pediatric Pain Tool has demonstrated *alternate forms reliability* as well (i.e. children's pointing; Van Cleve & Savedra, 1993), as well as *concurrent validity* for physical functioning, respiratory symptoms, digestive symptoms, and disease severity index in a sample of children with cystic fibrosis (Palermo, Harrison, & Koh, 2006). Similarly, while there were no results regarding pain locations included in its original publication (Varni, Thompson, & Hanson, 1987), *concurrent validity* of the Varni-Thompson Pediatric Pain Questionnaire was established, such that pain sites correlated with number of clinically active joints, pain intensity, and with disease severity (Von Weiss 2002). Therefore, our analyses were novel in establishing 2-week consistency, descriptive validity, and associative validity of a pain body map. Together with previous findings about different versions of body maps, these results highlight the unique utility of pain body maps in pediatric pain research and clinical practice.

The primary limitation of this study is the possibility of a selection bias. The data used for this study involved a secondary analysis of data obtained from a larger, ongoing study examining pain outcomes in a pediatric orthopedic surgery population. Not all children completed both baseline and follow-up body maps as reliability was not the purpose of the larger study. The small sample of children with acute painful conditions (e.g. fractures) did not complete a preoperative clinic visit prior to surgery, so the subsample of data regarding reliability of the body map was limited to children with chronic conditions. Replication in a larger study of children with acute injury would help to determine whether reporting of pain location is consistent in a broader population. That some children completed their baseline assessments on day of surgery may have differentially impacted their self-reported outcomes such as anxiety, which may have confounded results regarding associative validity. Additionally, the selection bias of surgically correctable orthopedic conditions may have limited generalizability of findings and clinical applications to other populations. Finally, due to the nature of data collection, we could not determine other aspects of reliability and validity. For instance, there was no additional measure of pain location, such as verbal report or pointing, so we could not assess concurrent reliability. Direct comparison of multiple forms of body map tools currently in use in research could help inform specific utility of differing formats. This might include more specific body sites such as fingers and toes if the purpose is to identify specific arthritic or inflammatory conditions. However, the good correspondence between pain locations on the body map and diagnostic site (descriptive validity) may mitigate this concern.

Future directions for this research could focus further assessment of reliability and validity of body map and other pain location tools, and on recovery trajectories and centralization of pain. Specifically, given growing interest in pain widespreadedness and characteristic phenotypes of patient populations, and how widespread pain is associated with functional impairment, future research might examine the trajectory of widespread pain as it relates to postsurgical recovery or chronic pain rehabilitation (Sieberg et al., 2013; Norris, Deere, Tobias, & Crawley, 2017; Rabbitts & Fischer, 2017). Furthermore, reliability and validity of the body map can be further assessed pre and post-surgically. Additionally, research may investigate the connection between indication of widespread pain on a body map and the potential for centralization of pain.

Further validation of the body map may facilitate general clinical utility of the tool. For instance, clinical teams can comprehensively address pain reports that may not typically be assessed in relation to specialty evaluation. This may help identify children with more centralized, widespread pain conditions that may present for inpatient or outpatient evaluation of specific body parts. This identification can lead clinicians to addressing the widespread pain in an integrative, multidisciplinary team-based approach, or refer to a pain-focused clinic. Similarly, pain-focused clinics may be better able to assess and track the degree of widespreaded pain with a validated pain body map as youth participate in intervention programs. Identifying youth with pain widespreadedness in the context of the high preoperative pain and symptom profile (Voepel-Lewis et al., 2017) by multidisciplinary clinical teams can possibly lead to optimal outcomes for youth vulnerable to chronification of pain.

These results regarding reliability and validity of the two-sided body map are promising and shed light on future clinical and research utility. Longitudinal examination of body map consistency to determine trajectories of pain widespreadedness with or without interventions may shed light on the association with or development of chronic or centralized pain syndromes in youth.

Disclosures:

Dr. Foxen-Craft, Dr. Scott, Dr. Kullgren, Ms. Philliben, Ms. Hyman, Ms. Dorta, Dr. Murphy, and Dr. Voepel-Lewis have nothing to disclose.

Author Contributions:

Dr. Foxen-Craft and Dr. Voepel-Lewis take responsibility for the integrity of the work as a whole, from inception to published article.

Dr. Foxen-Craft made substantial contributions to: 1) conception, design, analysis and interpretation of data, 2) drafted the article, and 3) made final approval.

Dr. Scott made substantial contribution to: 1) conception, design, analysis, and interpretation of data, 2) critically revision for important intellectual content, and 3) made final approval.

Dr. Kullgren made substantial contribution to: 1) conception and design, 2) critical revision for important intellectual content, and 3) made final approval.

Ms. Philliben, Ms. Hyman, and Ms. Dorta made significant contributions to: 1) conception and design, and acquisition of data, 2) critical revision, and 3) final approval of the version to be published.

Dr. Murphy made contributions to 1) conception, 2) critical revision, and 3) final approval of the version to be published.

Dr. Voepel-Lewis made substantial contributions to: 1) conception, design, acquisition of data, analysis and interpretation of data, 2) critical revision for important intellectual content, and 3) made final approval.

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Table 1. Characteristics of the sample

	Baseline (n = 130)
	M(SD)
Age	14.32 (1.83)
	n(%)
Demographics	
Female	84 (64.6)
Male	46 (35.4)
Caucasian	113 (86.9)
Black	10 (7.0)
Asian	1 (0.7)
Other	5 (3.8)
Missing	1 (0.7)
Pain widespreadedness	
0-2 regions	56 (43.1)
3 regions	38 (29.2)
4 regions	18 (13.8)
5 regions	18 (13.8)
Diagnosis	
Scoliosis	100 (77.0)
Injury/Fracture	18 (13.9)
Deformity/limb discrepancy	12 (9.4)
Diagnostic site	
Lower back	1 (2.2)
Mid to lower back	76 (58.5)
Mid to upper back	23 (17.7)
Lower extremity	21 (16.2)
Upper extremity	9 (6.9)

Table 2. Agreement between baseline and follow-up body map reports by site

Body Site	Agreed: Pain absent at both times (n)	Agreed: Pain present at both times (n)	Percent agreement	κ
L Shoulder Girdle	71	7	95.12%	.75**
R Shoulder Girdle	62	9	86.59%	.54**
L Arm Upper	78	1	96.34%	.39**
R Arm Upper	77	1	95.12%	.31*
L Arm Lower	76	2	95.12%	.48**
R Arm Lower	77	2	96.34%	.55**
L hip	72	4	92.68%	.54**
R hip	76	1	93.90%	.26*
L leg upper	74	2	92.68%	.37**
R leg upper	76	4	97.56%	.79**
L leg lower	73	4	93.90%	.58**
R leg lower	74	4	95.12%	.64**
L Knee	73	3	92.68%	.46**
R Knee	71	8	96.34%	.82**
L Jaw	80	1	98.78%	.66**
R Jaw	80	1	98.78%	.66**
Chest	77	0	93.90%	-.03
Abdomen	67	9	92.68%	.71**
Neck	63	12	91.46%	.72**
Back Upper	30	34	78.05%	.56**
Back Middle	20	47	81.71%	.59**
Back Lower	34	30	78.05%	.56**
Head	62	12	90.24%	.69**

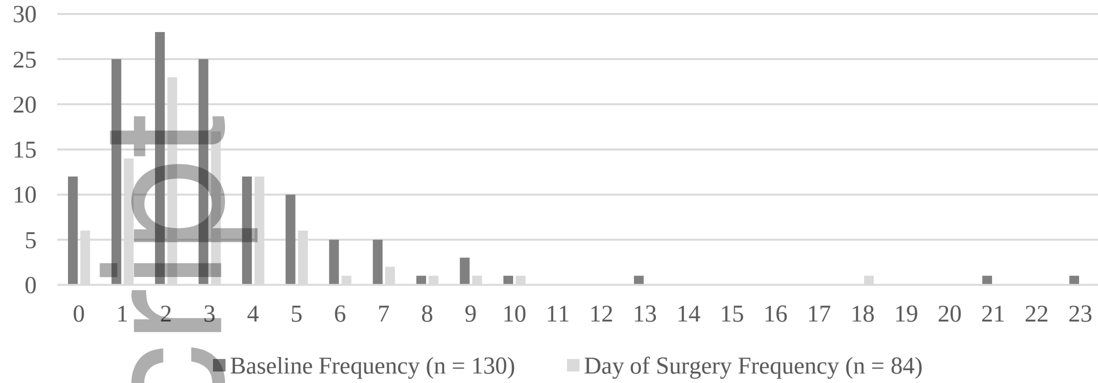
Note: L = Left, R = Right, *p < .05, **p < .001

Table 3. Associations between baseline patient factors and discrepancy of body map scores between preoperative clinic visit and day of surgery.

	r or rs	p
Highest pain intensity in past week	.31	.004**
Widespread pain	.39	.001**
Duration of time between assessments	-.04	.72
Age	-.07	.51
Pain duration	-.17	.12
Neuropathic pain	-.02	.84
Catastrophizing	.02	.88
Mobility/functioning	-.11	.34
Pain interference	-.04	.75
Depression	.05	.64
Fatigue	-.01	.93

Note. *p < .05, **p < .001

Figure 1. Distribution of body map total scores.



Note: Baseline frequency includes the entire sample, day of surgery follow up scores include only those who completed a second survey.

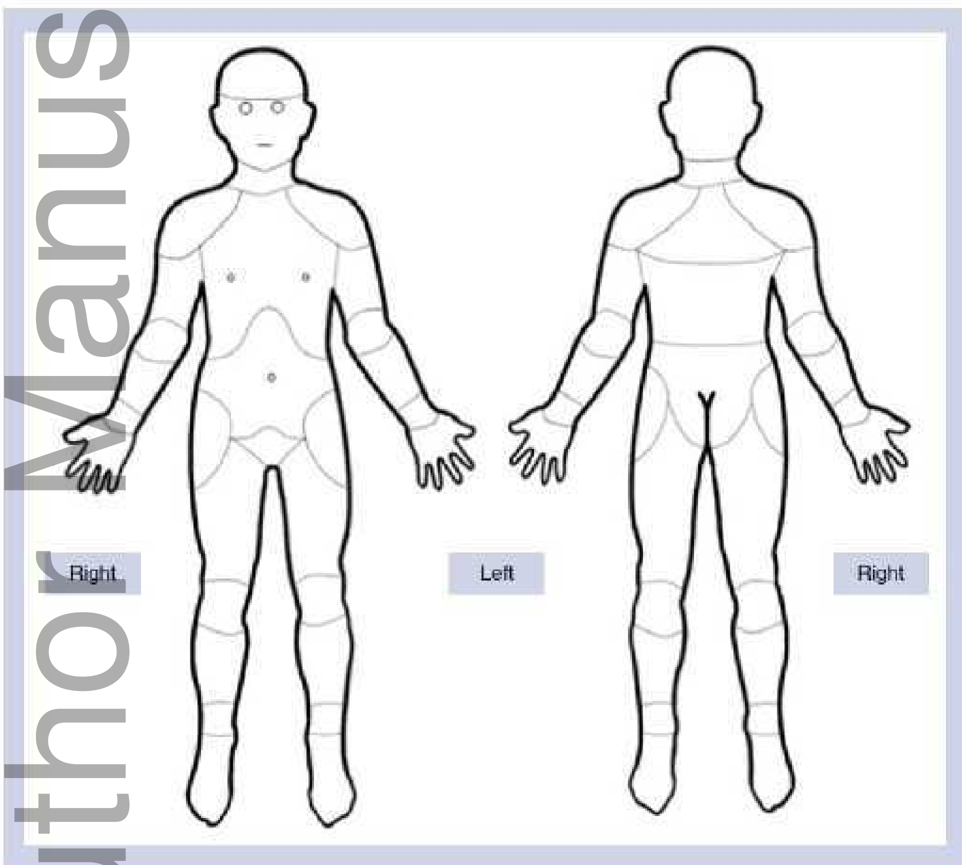
DATE: ___________ ID ___________

2. Show the body parts where you have had pain or tenderness by:

a. X all parts of your body where you have had pain in the past 6 months *(put an X on the wrist if it has hurt or felt tender or sensitive)*

b. Circle the part(s) where you have had the most pain in the past 6 months.

c. Color the part(s) where you have had pain in the past week.



X here if No Pain: ☐