Does format matter for comprehension of a facial affective scale and a numeric scale for pain by adults with Down syndrome?

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ABSTRACT
People with intellectual disabilities are at high risk for pain and have communication difficulties. Facial and numeric scales for self-report may aid pain identification. It was examined whether the comprehension of a facial affective scale and a numeric scale for pain in adults with Down syndrome (DS) varies with presentation format. Adults with DS were included (N = 106, mild to severe intellectual disabilities, mean age 37 years), both with (n = 57) and without (n = 49) physical conditions that may cause pain or discomfort. The Facial Affective Scale (FAS) and a Numeric Rating Scale (NRS) were compared. One subgroup of participants (n = 50) had to choose the two items within each scale to indicate ‘least pain’ and ‘most pain’. The other subgroup of participants (n = 56) had to order three faces of the FAS from ‘least pain’ to ‘most pain’, and to answer questions about the magnitude of numbers for the NRS (in addition to choosing the numbers that represented ‘least pain’ and ‘most pain’). Comprehension percentages were compared between two subgroups. More participants understood the FAS than the NRS, irrespective of the presentation format. The comprehension percentage for the FAS did not differ between the least-most extremes format and the ordering/magnitude format. In contrast, comprehension percentages for the NRS differed significantly between the least-most extremes format (61%) and the ordering/magnitude format (32%). The inclusion of ordering and magnitude in a presentation format is essential to assess thorough comprehension of facial and numeric scales for self-reported pain. The use of this format does not influence the number of adults with DS who pass the comprehension test for the FAS, but reduces the number of adults with DS who pass the comprehension test for the NRS.

Keywords: pain assessment, facial affective scales, numeric rating scales, Down syndrome, adults.
The ability to self-report pain is important for autonomous functioning of people with intellectual disabilities. Because people with intellectual disabilities benefit from the use of pictures to communicate about abstract concepts [22] and because people with Down syndrome (DS) have stronger visual-spatial abilities than verbal abilities [12], scales for self-report of pain might facilitate communication about pain experience. This is clinically relevant, because people with DS have a high risk for painful conditions, such as musculoskeletal problems, gastroesophageal reflux disease, and oral diseases [11,19,21].

Little research has been done on the usefulness of scales for self-report of pain in the intellectual disabilities population. LaChapelle, Hadjistavropoulos, and Kenneth (1999) showed that 65% of adults with intellectual disabilities were able to understand a scale with which pain intensity can be reported by positioning a plastic slide on the side that is coloured from white to dark red; the chosen position corresponds to a number ranging from 0 to 10 on the back side (Coloured Analogue Scale, CAS [18]). It was however not clear how comprehension of the CAS was tested in that study. Tests of comprehension in people with cognitive impairment traditionally consist of asking participants to indicate ‘least pain’ and ‘most pain’ on the scale with the scale items in the correct order (e.g., [20]). This method has been criticized, because the use of unordered scale items for the test would more accurately represent the participant’s comprehension of the scale [13]. ‘Comprehension’ in this context refers to the ability to understand the ordinal position of the scale items such as numbers or faces, not the ability to translate the own pain experience into one of the scale items.

A self-report evaluation procedure has been developed, in which children with intellectual disabilities had to put five different sized blocks, five visually presented numbers, and three face drawings in the correct order before they were considered to comprehend a numerical rating scale [9]. This procedure appeared to be difficult: only 7 out of 20 children with mild intellectual disabilities and 3 out of 6 children with borderline intellectual disabilities passed all tests, while none of the 21 profound to moderate children passed the test. In contrast, a study with adults with intellectual disabilities showed that they were able to arrange three blocks in correct order of increasing pain, to place the three blocks along a pain
ruler similar to the CAS, and to use the pain ruler to indicate pain intensity on three photographs of facial expression [4]. To sum, comprehension tests for facial and numerical scales may be feasible in adults with intellectual disabilities, and comprehension tests are needed that contain a detailed approach of magnitude and ordinal position.

In the present study, it was examined whether the comprehension of facial and numeric scales for pain in adults with DS varied with presentation format. To that end, a least-most extremes format and a ordering/magnitude format of the comprehension tests were compared for a facial affective scale and a numeric rating scale. ‘Comprehension’ refers in this study to the ability to understand the ordinal position of the scale items.

MATERIAL AND METHODS

Study design
The design was an observational study in adults with DS. The participants of the present study were the first enrolling in a larger study on the relationship between pain experience and cognitive functioning in adults with DS. The study protocol was approved by the medical ethical committee of VU University Medical Centre Amsterdam (research file: NL33540.029.11 2011/134).

Participants
Participants were recruited from 14 care centres for people with intellectual disabilities with permission from the Management Board of the care centres. Before the start of the study, inclusion and exclusion criteria were assessed by the care centre’s caregivers and behaviour specialists. Inclusion criteria were an estimated IQ of at least 35, an estimated level of mild or moderate intellectual disabilities, and the capability to speak and understand Dutch. Exclusion criteria were neurological disorders, a moderate or severe stage of dementia, visual impairments or hearing loss that would hamper the tests, and the use of antipsychotics, anticonvulsants, or antidepressants. To be included in the study, participants had to provide informed consent. If there was doubt regarding their capacity to provide informed consent, informed consent was also required from
parents or guardians. Demographic and medical characteristics of the participants are presented in Table 1.

Material

**Estimated level of intellectual disability**

The Social Functioning Scale for Intellectual Disability (Sociale Redzaamheidsschaal voor Zwakzinnigen, SRZ [15]; Sociale Redzaamheidsschaal voor Zwakzinnigen Plus, SRZ-P [14]) was completed by caregivers to assess the estimated level of intellectual disabilities. The scale includes items assessing social and cognitive abilities and activities of daily living, in which the level of functioning is higher in the SRZ-P. Participants of whom only the SRZ-P was available were identified as having a mild level of intellectual disabilities according to the SRZ. In this way, the levels of intellectual disabilities for all participants were based on the abilities in the SRZ. The SRZ has been used in other DS studies [6,7].

**Possible indication for dementia**

In accordance with the national recommendations [23], the participants aged 40 years and older were screened for the possible presence of dementia. To that end, the scores of the SRZ/SRZ-P and the Dementia Questionnaire for Intellectual Disability (DMR) [8] completed during the study were compared to scores of at least six months ago derived from files of the care centres [8]. When the difference for both the SRZ/SRZ-P and the DMR was statistically significant according to cut-offs in the manuals, then the individual had screening scores indicating possible dementia (for further details, see [8,14,15]). When no old scores were available, then the caregivers filled in a DVZ and SRZ/SRZ-P at least six months after the completion close to the test assessment, and the difference in scores were compared between these two moments in time.

**Medical information**

Caregivers used medical files to provide the researcher with information about analgesic medication, thyroid medication, diabetes, depression, and physical conditions that may cause pain or discomfort. One physiotherapist (E.J.A.S.), one general physician, and two specialized physicians for people with intellectual disabilities rated whether the reported physical conditions were expected to cause possible pain or discomfort. The two specialized physicians for people with
**TABLE 1**  
Participant characteristics of the sample with Down syndrome: comparison between participants in the first subgroup (FIRST) and participants in the second subgroup (SECOND)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>First</th>
<th>Second</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years: Range Mean (± SD)</td>
<td>19 – 64</td>
<td>19 – 65</td>
<td>-</td>
</tr>
<tr>
<td>Gender (% male)</td>
<td>64</td>
<td>43</td>
<td>*χ²(1) = 4.74, <em>p = .029</em></td>
</tr>
<tr>
<td>Estimated level of ID (% mild/moderate/severe)</td>
<td>22/64/14</td>
<td>43/48/9</td>
<td>Cramer’s <em>V</em> = 0.22, approx. *p = .072</td>
</tr>
<tr>
<td>Analgesic medication (% users)</td>
<td>2</td>
<td>9</td>
<td>Fisher’s exact test, *p = .21</td>
</tr>
<tr>
<td>Thyroid medication (% users)</td>
<td>38</td>
<td>36</td>
<td>*χ²(1) = 0.06, <em>p = .81</em></td>
</tr>
<tr>
<td>Presence of symptoms of depression (%)</td>
<td>2</td>
<td>4</td>
<td>Fisher’s exact test, *p = 1.00</td>
</tr>
<tr>
<td>Presence of possible indication for dementia (%)</td>
<td>5</td>
<td>19</td>
<td>Fisher’s exact test, *p = .20</td>
</tr>
<tr>
<td>Presence of diabetes (%)</td>
<td>8</td>
<td>0</td>
<td>Fisher’s exact test, <em>p = .046</em></td>
</tr>
<tr>
<td>Presence of physical conditions pain/discomfort (%)</td>
<td>56</td>
<td>52</td>
<td>*χ²(1) = 0.19, <em>p = .66</em></td>
</tr>
</tbody>
</table>

*Note.* * = statistically significant difference. ID = intellectual disability. Physical conditions pain/discomfort = physical conditions that may cause pain/discomfort.
intellectual disabilities first reached consensus, resulting in one list of ratings from the physiotherapist, one list from the general physician, and one list from the two specialized physicians for people with intellectual disabilities. A physical condition was ultimately rated as possibly causing pain or discomfort when at least two of the three professionals indicated that this could be the case.

**Scales for self-report of pain: least-most extremes format of comprehension test**

Participants passed the test of comprehension per scale only when they gave the answers that we considered being correct (see Table 2).

The Facial Affective Scale (FAS) [18] includes line drawings of nine faces, ranging in expression from no distress to most severe distress (see Supplementary Figure 1). The participant’s score is reflected in the numerical value on the back of the scale. The values were determined in a previous study [16,17] and correlate to pain affect on a scale from 0 to 1: .04 is the maximum positive affective value for the least pain and .97 is the maximum negative affective value for the most pain. In the test of comprehension, participants were asked to indicate which face of the FAS showed ‘least pain’ and which ‘most pain’, while the faces were in the correct order of the original scale.

**TABLE 2**

Correct answers for passing the comprehension test per scale

<table>
<thead>
<tr>
<th>Scale</th>
<th>Correct answer (= ‘understands’, ‘passed the test’)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAS least-most extremes format&lt;sup&gt;a&lt;/sup&gt;</td>
<td>No pain: .04 or .17, Most pain: .85 or .97</td>
</tr>
<tr>
<td>FAS ordering/magnitude format&lt;sup&gt;b&lt;/sup&gt;</td>
<td>Order: 1-2-3 (presented: 3-1-2 corresponding to .85 - .17 - .75)</td>
</tr>
<tr>
<td>NRS least-most extremes format&lt;sup&gt;a&lt;/sup&gt;</td>
<td>No pain: 0 or 1, Most pain: 9 or 10</td>
</tr>
<tr>
<td>NRS ordering/magnitude format&lt;sup&gt;b&lt;/sup&gt;</td>
<td>‘Which is larger: 2 or 8?’, ‘Which is larger: 6 or 4?’, no pain: 0 or 1, Most pain: 9 or 10</td>
</tr>
</tbody>
</table>

*Note.* FAS = Facial Affective Scale, NRS = Numeric Rating Scale (Coloured Analogue Scale numeric side). <sup>a</sup> First subgroup. <sup>b</sup> Second subgroup.
The Coloured Analogue Scale for pain (CAS) [18] contains a coloured and a numerical side. Both sides reflect scores ranging from 0 to 10, with a higher score indicating more pain. A plastic slide can be placed vertically on a position corresponding to the experienced pain intensity. In the present study, only the numerical scale was used (see Supplementary Figure 2). Therefore, this scale is referred to in the rest of the manuscript as 'Numeric Rating Scale (NRS)'. To test comprehension, participants were asked to indicate at what level the slide should be positioned when a person has 'least pain' and at what level when someone has 'most pain'.

**Scales for self-report of pain: ordering/magnitude format of comprehension test**

In the second subgroup, a different format of comprehension was used for the FAS and NRS (see Table 2). It was noticed that participants who passed the test of comprehension for the FAS subsequently had difficulties using the entire range of the nine faces to choose a face corresponding to their own pain experience. This was believed to be caused by the comprehension test, in which they only had to focus on the two faces of 'least pain' and 'most pain'. The test of comprehension for the FAS was therefore adjusted to better assess the understanding of the whole range of faces: three faces of the FAS representing mild pain, moderate pain, and severe pain were presented in the order of severe pain, mild pain, and moderate pain (see Supplementary Figure 3), while the participant was asked to arrange the faces in the correct order, that is from mild to severe pain. The test of comprehension for the NRS was adjusted to better assess the understanding of a numerical scale. Two questions were added that focused on magnitude of numbers (see Table 2). The questions contained a verbal presentation of numbers and did not require material such as numbered cards. The questions were asked before showing the NRS.

Please note that instructions for participants, specified per comprehension test and per scale, can be found in the Supplementary Information.

**Statistical analysis**

Statistical analyses were performed using Statistical Package for the Social Sciences version 20 (SPSS Statistics 20). Descriptive characteristics of the two subgroups were compared with General Linear Model for normally distributed continuous
variables, with a Cramer’s $V$ test for ordinal variables, with a Chi-square test for nominal variables, and with a Fisher’s exact test for nominal variables when more than 20% of the cells had expected count less than 5 (see Table 1). Percentages of comprehension for the same scale were compared between the two subgroups with a Chi-square test or, when more than 20% of the cells had expected count less than 5, with a Fisher’s exact test. Percentages of comprehension for different scales in the same subgroup were compared with a McNemar test. The level of statistical significance was set at $\alpha = .05$ with rejection of the null-hypothesis when two-sided $p < 0.05$.

**RESULTS**

**Demographic and medical characteristics of participants**

Ultimately, 106 out of 123 people with DS met the criteria for participation. In the sample of 106 participants, the mean age was 37 years, and 56 participants were male (53%). Most of the participants (56%) had a moderate level of intellectual disabilities, corresponding to an IQ of 35 to 50 [1]. Of the 49 participants aged 40 years and older, 6 participants had screening scores indicating possible dementia. Of the 12 participants in the entire sample with severe intellectual disabilities, 5 (42%) did not comprehend the FAS and 8 (67%) did not comprehend the NRS. Of the six participants in the entire sample with possible dementia, one (17%) did not comprehend the FAS and three (50%) did not comprehend the NRS.

Six participants of the entire sample used analgesic medication. Acetaminophen was provided for pain due to hip dysplasia, osteoarthrosis, spasm, and rough backside of the knee ligament. Diclofenac was provided for painful knees due to long knee ligaments. A combination of acetaminophen and diclofenac was provided for pain due to dysplasia and “wearing” of hips, according to the caregivers. Thyroid medication, used by the 39 participants, was Thyrax® ($n = 32$), Euthyrox® ($n = 5$), a combination of Thyrax® and Euthyrox® ($n = 1$), or a combination of Thyrax® and Levothyroxine® ($n = 1$). Of the entire sample, three participants had symptoms of depression and four participants had diabetes. Physical conditions that may cause pain or discomfort were found in 57 participants and are described in Table 3.
Table 1 shows the demographic and medical characteristics of participants in the first subgroup \((N = 50)\) and second subgroup \((N = 56)\). The first subgroup consisted of more men than the second subgroup \((\chi^2(1) = 4.74, p = .029)\). The former group also contained more participants with diabetes than the latter group \((\text{Fisher's exact test, } p = .046)\). The groups did not differ in any of the other characteristics (see Table 1).

**Comprehension percentages for the FAS and NRS: first subgroup versus second subgroup**

In the first subgroup, the percentage of 76% comprehension for the FAS was significantly higher than 61% comprehension for the NRS \((\text{McNemar test, } p = .039)\). In the second subgroup, the percentage of 68% comprehension for the FAS was significantly higher than 32% comprehension for the NRS \((\text{McNemar test, } p < .001)\). Comprehension percentages for the FAS in the first subgroup (76%) and the second subgroup (68%) did not differ significantly \((\chi^2(1) = 0.86, p = .35)\). In contrast, comprehension percentages for the NRS in the first subgroup (61%) and the second subgroup (32%) differed significantly, in which the percentage in the second subgroup was lower \((\chi^2(1) = 8.42, p = .004)\).

Of the participants in whom both the FAS and the NRS were assessed \((n = 46 \text{ in the first subgroup, } n = 56 \text{ in the second subgroup})\), at least one of the two scales was comprehended by 78% in the first subgroup and 71% in the second subgroup. This difference was not statistically significant \((\chi^2(1) = 0.62, p = .43)\). The percentage of participants who understood none of the scales in the first subgroup (22%) and in the second subgroup (29%) was also not significantly different \((\chi^2(1) = 0.62, p = .43)\).

Having a physical condition that may cause pain or discomfort was not related in the entire sample to comprehension of the FAS \((\chi^2(1) = 0.24, p = .62)\) or NRS \((\chi^2(1) = 0.25, p = .62)\). Of the participants aged 40 years and older, no relationship was found between having possible dementia and comprehension of the FAS \((\text{Fisher's exact test, } p = .65)\) or NRS \((\text{Fisher's exact test, } p = .68)\). These results may have been influenced by the small number of participants \((n = 6)\) with possible dementia.

Because participants in the first part and second subgroup differed in prevalence of men and diabetes, it was analyzed in the entire sample whether
## TABLE 3
Physical conditions that may possibly cause pain or discomfort and that were present in the participants according to caregivers

<table>
<thead>
<tr>
<th>Physical conditions</th>
<th>n</th>
<th>Physical conditions</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skin condition (callus, psoriasis, eczema, boils, inflamed fingertips, abrasive skin irritation, erysipelas, lichen simplex chronicus, piles, hidradenitis suppurativa, open wounds)</td>
<td>15</td>
<td>Bone necrosis in knee and/or hip</td>
<td>2</td>
</tr>
<tr>
<td>Constipation</td>
<td>6</td>
<td>Stomach pain (e.g., due to diaphragmatic rupture)</td>
<td>1</td>
</tr>
<tr>
<td>Knee pain (e.g., due to meniscus operation, painful knee ligaments, rough back side of patella, overweight, or difference in length of the legs)</td>
<td>6</td>
<td>Shoulder pain due to bursitis</td>
<td>1</td>
</tr>
<tr>
<td>Deviant foot position (pes equinus, pes equinovarus adductus, halgus valgus)</td>
<td>5</td>
<td>Neck pain (due to tension)</td>
<td>1</td>
</tr>
<tr>
<td>Back pain (due to wearing of vertebrae, deviant posture of knee, overweight, hypermobility, or physical activity with short stature of 1.45m)</td>
<td>5</td>
<td>Neck deformation*</td>
<td>1</td>
</tr>
<tr>
<td>Gout</td>
<td>4</td>
<td>Patella luxation</td>
<td>1</td>
</tr>
<tr>
<td>Chronic inflammation of gums</td>
<td>4</td>
<td>Spastic foot and leg</td>
<td>1</td>
</tr>
<tr>
<td>Bowel disease/irregular bowel movement/intestine problems</td>
<td>4</td>
<td>Fungal infection</td>
<td>1</td>
</tr>
<tr>
<td>Hip dysplasia</td>
<td>3</td>
<td>Tooth ache during chewing hard food (4 implants in upper jaw)</td>
<td>1</td>
</tr>
<tr>
<td>Stiff/worn hip joints</td>
<td>2</td>
<td>Pain in upper jaw (no teeth present anymore)*</td>
<td>1</td>
</tr>
<tr>
<td>Muscle pains in arms, shoulders, or legs (due to physical activity or inactivity)</td>
<td>2</td>
<td>Varicose veins</td>
<td>1</td>
</tr>
<tr>
<td>Scoliosis</td>
<td>2</td>
<td>Subcutaneous inflammation</td>
<td>1</td>
</tr>
<tr>
<td>Osteoarthrosis</td>
<td>2</td>
<td>Albers Schönbergs disease</td>
<td>1</td>
</tr>
<tr>
<td>Eye irritation (due to lenses or due to stitches after cornea transplantation)</td>
<td>2</td>
<td>Hip pain*</td>
<td>1</td>
</tr>
<tr>
<td>Gastroesophageal reflux disease (e.g., causing pain in stomach and chest)</td>
<td>2</td>
<td>Menstruation pain/discomfort</td>
<td>1</td>
</tr>
</tbody>
</table>

*Note.* * = cause unspecified. n = number of participants in whom the specific physical condition is present according to caregivers on the basis of information from the medical files. Some participants had conditions in several categories (e.g., a prosthesis and a skin condition) or several conditions in the same category (e.g., two prostheses).
these differences were related to the results concerning comprehension of the scales. Gender was not related to comprehension of the FAS ($\chi^2(1) = 0.004, p = .95$) or NRS ($\chi^2(1) = 0.43, p = .51$). Similarly, no relationship was found between diabetes and comprehension of the FAS (Fisher’s exact test, $p = .58$) or NRS (Fisher’s exact test, $p = .09$).

**DISCUSSION**

**Discussion of the current results**

Our aim was to examine whether the comprehension of facial and numeric scales for pain in adults with DS varied with presentation format. A first finding is that more participants comprehended the FAS than the NRS, irrespective of the presentation format. It should be emphasized that this is not a comparison between a facial and a numeric scale that measure the same construct (i.e., pain intensity), but a comparison between two different scales: a facial affective scale for pain and a numeric rating scale for pain intensity. The finding that more participants comprehended the FAS than the NRS could mean that adults with DS have generally a better comprehension of faces than numbers and/or have specifically a better comprehension of pain affect than pain intensity. Our finding cannot be compared with earlier studies concerning scales for self-report of pain in people with intellectual disabilities, because no clear comparison has been made between comprehension of facial and numeric scales [4,9]. The finding is however in contrast with a study concerning elderly people with dementia, in which fewer participants comprehended a facial scale than a numeric scale [13]. To be specific, fewer participants were able to order the seven faces of the Faces Pain Scale (FPS) than those who completed a test about the magnitude of numbers [13]. Although they are both a facial scale used in pain assessment, the comparison between the FAS and FPS is not entirely justified due to differences in construct and range of the scales: the FAS is a scale for pain affect [18] with faces ranging from a broad smiling face to a severe crying face, while the FPS is a scale for pain intensity [2] ranging from a neutral face to a severe crying face. The contrast between our finding and those of Kaasalainen and Crook (2004) may be explained by: 1) the larger difficulty to order seven faces from a neutral face to an extremely painful face (FPS) compared to arranging three faces from mild
pain to severe pain (FAS in the second subgroup of the current study), and 2) the smaller demand on visual imagination to complete a test for magnitude when the numbers are presented visually as in Kaasalainen and Crook’s study than when they are presented verbally as in the current study.

The most important finding is that assessing the participant’s comprehension of the NRS with the ordering/magnitude presentation format resulted in a lower percentage of people who passed the test of comprehension. The demographic and medical differences between participants in the two subgroups did not explain the results, since no statistically significant effects were found in the entire group between gender or diabetes and comprehension of the scales. As far as we know, no other studies addressed the comprehension of a numeric rating scale by first indicating values for ‘least pain’ and ‘most pain’: Scherder and Bouma (2000) tested the least-most extremes format only for the coloured side of the CAS and although Bromley and colleagues (1998) requested to place three blocks of different size along a pain ruler similar to the CAS, they did not explicitly asked which value of the pain ruler correspond to ‘least pain’ and which to ‘most pain’.

The percentage of participants who comprehended the FAS was not changed by format of the comprehension test. This is in contrast to the considerably smaller percentage of elderly with dementia who were able to order the faces of the FPS, that is 24% of 30 participants with mild dementia and 11% of 40 participants with moderate dementia, than the percentage who were able to indicate the face for ‘least pain’, that is 83% of 30 participants with mild dementia and 42% of 40 participants with moderate dementia [13]. The contrast with our finding may be explained by the earlier mentioned difficulty to order the faces of the FPS. Concerning the least-most extremes format for the FAS, the comprehension percentage of 76% in adults with DS is much higher than that of 50% observed in elderly with mild dementia and 20% in elderly with moderate dementia in a study with a comparable comprehension test [20].

At least one of the two scales was comprehended by 78% of the participants in the first subgroup and 71% of the participants in the second subgroup. This finding justifies the use of various scales for self-report of pain in individuals
with DS. Measures of both pain affect and pain intensity should be included in pain assessment.

**Limitations**

Two components have to be examined before using a scale for communication about pain experience: 1) whether someone comprehends the ordinal position of the scale items, such as numbers or faces, and 2) whether he/she can translate own pain experience into one of the scale items. The current study only addressed the first component. In other words, it is possible that people who pass a test of comprehension as described in the current study still have difficulty to reflect on the own pain experience and to choose one of the scale items.

The current study is limited in the fact that it only includes adults and only people with DS, while it is relevant for the entire intellectual disabilities population to examine whether the use of scales for self-report of pain is possible. Pain is also prevalent in children with intellectual disabilities [3] and in other causes of intellectual disability than DS, such as cerebral palsy [5,10].

Twelve participants of the current study had a severe level of intellectual disabilities, while one of the inclusion criteria was a mild to moderate level of intellectual disabilities. In the recruitment procedure, caregivers and behaviour specialists of the care centres selected possible participants on the basis of files and personal experience. In our data collection, the level of intellectual disabilities was estimated on the basis of one completed SRZ or SRZ-P. The fact that our sample contained participants with severe intellectual disabilities was the result of our recruitment procedure and/or our method to estimate the level of intellectual disabilities. Still, it was not likely that the presence of participants with severe intellectual disabilities influenced our results, because (1) they represented only 17% of the participants who did not comprehend the FAS and 14% of the participants who did not comprehend the NRS, and (2) participants in the first part and second subgroup did not differ in the level of intellectual disabilities.

To prevent a ceiling effect, we could have differentiated the SRZ level of mild intellectual disabilities more by also using the levels of intellectual disabilities according to the SRZ-P for everyone with a SRZ total scale score of 9 and higher, as is recommended in the SRZ manual. This would, however, result in two measures of level intellectual disabilities (i.e., according to the SRZ and the SRZ-P), with each
a different meaning of the levels severe – moderate – mild intellectual disabilities. Because this may lead to confusion and unclear analyses, it was necessary to define participants of whom only a SRZ-P was available as having a mild level of intellectual disabilities according to the SRZ.

**Conclusion and recommendation**

The arrangement of the FAS faces from ‘least pain’ to ‘most pain’ is a more detailed approach, while the amount of information from the three faces is still manageable. However, it can be concluded that only the detailed presentation format of the NRS matter: adding questions about magnitude of numbers results in a smaller proportion of adults with DS who passed the test of comprehension.

Current findings await test of generalizability to populations of children with intellectual disabilities and adults with intellectual disabilities by other causes than DS. In addition, assessments of comprehension should be developed for other scales to report pain and tested in people with intellectual disabilities. This is important to enlarge the probability that an individual with intellectual disabilities comprehends at least one scale and to find an alternative for the participants of the current study who comprehended neither of the two scales. Clinicians are recommended to use at least the least-most extremes presentation formats for the FAS and NRS as described in this study. Ideally, comprehension of the ordinal position of the scale items should be tested before scales are applied to assess pain experience. There is however a paucity of information about the ability of people with intellectual disabilities to reflect on the own pain experience and to choose subsequently the corresponding items of self-report scales. Research on that topic is both clinically relevant and urgent.

**REFERENCE**


SUPPLEMENTARY FIG. 1
Facial Affective Scale (FAS) [18]: front as seen by the participants (1) and back with numerical values (2). The maximum negative affective value equals .97 and the maximum positive affective value equals .04. Permission for use obtained from P.A. McGrath. Photocopy of test material (first author). Patricia A. McGrath, Pain in Children – Appendix: Pain Assessment, Guilford, New York, United States of America, Copyright © 1990.
SUPPLEMENTARY FIG. 2
Coloured Analogue Scale for pain (CAS) [18]. Permission for use obtained from P.A. McGrath. 'Photocopy of test material (first author). Patricia A. McGrath, Pain in Children – Appendix: Pain Assessment, Guilford, New York, United States of America, Copyright © 1990.

SUPPLEMENTARY FIG. 3
Adjusted Facial Affective Scale (FAS): as test of comprehension, participants were requested to arrange the faces from ‘least pain’ to ‘most pain’ (the faces of the correct order correspond to the McGrath’s values of .17, .75, and .85).
Instructions for participants

FAS first subgroup
Please take a look at these faces. They are all different. Which face has no pain at all, do you think?
And which face has the most pain of all these faces?
When not the face with McGrath's value of .04 is chosen in response to the first question: Is there a face with less pain than this one? When not the face with McGrath's value of .97 is chosen in response to the second question: Is there a face with more pain than this one?

FAS second subgroup
Please take a look at these faces. They are all different. Could you place them in order from a bit of pain here [researcher points to the side of the Table that is left for the participant] to a lot of pain here [researcher points to the side of the Table that is right for the participant]?
When the participant fails: Which of these faces has the least pain?... Good! We want to place the faces from a bit of pain here to a lot of pain here. So, where do we have to place this face?... Yes, here. Which of these two faces has the most pain?... Good! Where do we have to place it?... Good! And this face? Does it have more pain or less pain than this one? [researcher points to the face representing mild pain, which is placed on the left side of the Table] Yes, more pain than this one, so it has to be placed between the faces [researcher places the representing moderate pain between the other two faces]. Now we have three faces from a bit of pain to a lot of pain.

NRS first subgroup
Here is a row with numbers from zero up to including ten. You can move this plastic piece and place it on a number, do you see? [researcher demonstrates and then places the plastic piece in the middle] If someone has no pain at all, on what number do we have to place the piece? Please show me [researcher writes down the exact number on which the red line in the middle of the plastic piece lies, for example 3.75, and then moves the piece back to the middle of the scale]. And if someone has lots and lots of pain, on what number do we have to place the piece
then? Please show me [researcher writes down the exact number on which the red line in the middle of the plastic piece lies].

**NRS second subgroup**

Which is larger, two or eight? [correct answer: 8]

Which is larger, six or four? [correct answer: 6]

[Researcher continues with the NRS, irrespective of the answers]

*Here is a row with numbers from zero up to including ten. You can move this plastic piece and place it on a number, do you see? [Researcher demonstrates and then places the plastic piece in the middle]*

If someone has no pain at all, on what number do we have to place the piece? Please show me [researcher writes down the exact number on which the red line in the middle of the plastic piece lies, for example 3.75, and then moves the piece back to the middle of the scale]. And if someone has lots and lots of pain, on what number do we have to place the piece then? Please show me [researcher writes down the exact number on which the red line in the middle of the plastic piece lies].