The pain limitation list (PLL): a study of concurrent validity and relationship between PLL and age and gender

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Sammanfattning

Syfte: Syftet för denna studie var att undersöka samstämmig validitet mellan the Pain Limitation List (PLL) och the Functional Disability Inventory (FDI), samvariationen mellan ålder och PLL och ålder och FDI, skillnad mellan kön för PLL och FDI samt eventuella tak- eller golveffekter för de två testen.

Metod: Studien var en tvärsnittsstudie och hade en beskrivande korrelerande och jämförande design. 86 barn med långvarig smärta deltog i studien.

Resultat: Studien visade att PLL har en samstämmig validitet med FDI (r= -0,740, p<0,001), att det var en svag samvariation mellan FDI och ålder (r=0,249, p<0,021), ingen samvariation mellan PLL och ålder samt att det inte förelåg någon skillnad mellan könen i FDI och i PLL. Det fanns heller ingen tak- eller golveffekt för de två testen men det verkar som att PLL är något mer känslig för barn och ungdomar med mindre smärtrelaterad aktivitetsbegränsning.

Konklusion: Enligt denna studie har PLL samstämmig validitet. Men för att kunna använda PLL som ett pålitligt instrument behöver fler studier undersöka instrumentets reliabilitet och andra typer av validitet.

Key words: Children, Pain Limitation List, Functional Disability Inventory, pain disability, chronic pain.
Abstract

**Aim:** The aim of this study was to explore the concurrent validity between Pain Limitation List (PLL) and Functional Disability Inventory (FDI), the association between PLL and age and FDI and age, the difference between gender in PLL and FDI and possible floor or roof effects in the two tests.

**Method:** The study was a cross-sectional study and had a descriptive correlational and comparative design. 86 children with chronic pain participated in the study.

**Result:** The study showed that PLL had a concurrent validity with FDI ($r=-0.740$, $p<0.001$). There was a weak correlation between FDI and age ($r=0.249$, $p<0.021$) but PLL did not have a correlation with age and there was no difference between gender in PLL or in FDI. Also, there was no floor or roof effect for the two tests but it seems that PLL is slightly more sensitive for children and adolescents with less pain-related disability.

**Conclusion:** according to this study, PLL has a concurrent validity. But to be able to use PLL as a reliable instrument, more studies who explore reliability and other types of validity is needed.

**Key words:** Children, Pain Limitation List, Functional Disability Inventory, pain disability, chronic pain.
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BACKGROUND
International Association for the Study of Pain (IASP) defines pain as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. Pain is always subjective and can occur in the absence of tissue damage (1).

There are different classifications of pain. It can be acute, subacute or chronic depending on the duration of pain. It can be nociceptive, neurogenic, psychogenic, idiopathic or mixed form depending on the mechanism behind the pain. Finally, pain can be musculoskeletal, visceral or cutaneous depending on the localisation of the pain and for example postoperative or cancer-related depending on background of disease (2, 3).

Pain has been widely researched in adults. The knowledge and research about pain in children and adolescents, however, is less extensive. Since 1990 the interest to investigate pain in children and adolescents has increased and the incidence of chronic pain in children and adolescents is more common than previously thought (2,3).

Factors influencing the development and duration of pain
As mentioned earlier pain can be classified by the duration of pain. The three categories of this aspect is acute, subacute and chronic. Acute and subacute pain last for the first weeks and the pain classifies as chronic after 3 months. It is important to take into account that chronic pain is not irreversible but can dissolve (3).

Chronic pain is a complex condition where consequences of the pain are changes in the peripheral nervous system and in the central nerve system. This makes the condition more as a syndrome than a symptom and appears individually with many different interacting factors (2, 4). Examples of change in the nervous system are central sensitisation, long-term potentiation (LTP), disinhibition, pain facilitation and central plasticity (2). Chronic pain can cause a downregulation of the body’s own descending pain inhibitory system, a disinhibition. The pain can then be constant and generalized. Chronic pain activates entirely different parts of the brain compared to acute pain. In acute pain association factors lies in prefrontal cortex but chronic pain moves these factors to frontal cortex and amygdala, with the consequence of increased feelings of anxiety or fear.

Psychological factors play a great role in maintaining pain and the development of chronic pain is a complex combination of psychological and environmental factors. Examples of these psychological factors are avoidance behaviour of social and physical activities, catastrophizing, fear of pain, belief that pain means harm and that the pain needs to cease.
before resumption of normal activities (5). To explain this further, the fear-avoidance model can be used, that shows the importance of psychological and social factors in pain experience. An individual with an injury and acute pain normally get a warning signal and “normal” fear for the pain. Later, the individual moves the body part as normal as possible and as much as the pain allows. This result in reset movement and strength and, consequently, recovery from the injury. However, sometimes the pain is perceived differently. The individual then identifies the pain as a threat and develop catastrophizing and fear for the pain. The fear increases the attention to pain and activates the body’s defence system, which in turn can increase the pain. The fear can also cause avoidance of movements or activities that the individual thinks creates more pain. This behaviour is very easy to maintain and the individual can therefore develop a vicious circle of these steps, and make the pain chronic (6).

**Chronic pain in children and adolescents**

The development of the nociceptive system begins very early in the pregnancy, from week 7 to week 24, and early painful experiences in the childhood affect painful experiences in life later on (2, 7,8). However, it is not until in the teens that the nociceptive system is completely developed (2). A child doesn’t have the same cognitive development as an adult and that can explain why children get a greater pain experience during a vaccination or a cleaning of a wound. An adult can understand the pain and evaluate its threat while the child lacks this ability and therefore use its emotional system instead (4).

Earlier, it was thought that infants couldn’t feel pain because of the undeveloped nociceptive system and that pain in children was rarely chronic but today we know that the incidence of chronic pain in children and adolescents is higher than previously thought (2,4). Perquin et al. show in their study that head, abdomen and limb are the most frequent painful body parts in children with chronic pain (9).

**The consequences of pain in activity and participation for children and adolescents**

Pain can result in various consequences for the individual, both physical and psychosocial. Physical and functional factors caused by the pain are for example difficulty sleeping and walking, limiting tiredness and reduced movement and appetite. Physical and social factors are depression, increased dependence of others and social interactions (3). Pain in children can also cause school absenteeism, reduction or stopping of physical activity and other activities (10,11).
Studies have shown that pain is a particular barrier for children to participate in physical activity. Physical activity decreases the more pain localisations and inactive children reported more pain than active children (12,13). Another study demonstrates that pain intensity, worrying, ability to reduce pain, catastrophizing, behavioural distraction and externalizing affect pain-related disability (14).

How to measure pain in children and adolescents
When measuring pain in children and adolescent different scales can be used, depending on the child’s age and cognitive level. For the youngest children who can’t yet speak scales of pain-behaviour is being used (2,16). After 3 years of age, children can verbally express pain but have difficulties to estimate the amount of pain. Therefore, a scale customized for this is used. This scale is called Poker Chip Tool, where the children use 4 poker chips and grade the pain by choosing the number of poker chips equal to the level of the pain (4,17). In the years 4-6 and even 6-10 children can use Faces Pain Scales (FPS) which is a commonly used scale where the children choose face expressions according to the pain they experience (18). When the child is 6-10 years old the Numeric rating scale (NRS)/Visual analogue scale (VAS) can be used (19,20).

The scales are an easy way to estimate a child’s level of pain, however, they don’t show anything about the child’s functional disability and the difficulties the pain cause in everyday life.

Measuring of pain-related disability
There are several instruments that evaluate pain-related disability. Examples of instruments are Northwick Park neck pain questionnaire, The Roland–Morris Disability Questionnaire and the Oswestry Disability Questionnaire. These instruments, however, is developed for adults and not for children and adolescents. It is little studied about children and adolescent generally and there is a lack of good instruments for children with pain, since many instruments only measure the pain intensity and not the consequences the pain has on the daily activities in children and adolescents (21). There is also a lack of knowledge about factors influencing pain-related disability in children in primary care. Today there are mostly studies regarding secondary or tertiary care (22).

Functional Disability Inventory is one of the few measurements for children and adolescents with pain, that investigate pain-related disability. FDI was developed to measure a child’s deviation in physical and social activities relevant to the child and the questionnaire were
designed to be adequate to children in many different ages (23). Concerns about the instruments’ sensitivity to detect low degrees of disability has arised (21). Today there is a lack of measurement for pain-related disability for children and adolescents to choose from other than FDI. Based on this need the Pain limitation List (PLL) was developed. For a more detailed description of the FDI and the PLL, see Data collection in the method section.

Validity of a measurement
When a new measurement, in this case PLL, has been created it is important to investigate the test’s psychometric quality before it is adopted. One of these qualities is the validity of the instrument. Validity shows whether a test measure what it is meant to measure which is important for the clinical value of the test (24). There are several forms of validity. Content validity shows if the test covers the full domain of the topic of the test and is based on judgement from an expert panel. Construct validity is used to verify if a test follows a theoretical hypothesis about the construct. It is established in several ways, such as known-groups technique, but it always includes logical analyses and correlational testing predicted on established concepts. A third kind of validity is criterion-related validity, which is included in this study. This validity can be divided in two parts; predictive validity (which is not included in this study) and concurrent validity. Concurrent validity concerns the association between an instrument and an already validated instrument in the same domain as the new instrument is supposed to measure. The association can be calculated by using a correlational coefficient, ranging between -1 and 1. A strong correlation, with a coefficient of 0,7 or higher indicate validity for the new test (24,25).

Gender difference in children and adolescent with pain-related disability
Pain is more common and more intense in women. The pain is also more widely spread and has longer duration for women compared to men and the difference between gender is highest at fertile age. However, it has been shown that differences in gender also exists around age 12 (2). One report claims that it is about 70 % more common for girls to have musculoskeletal pain than boys and that the debut of pain is often at the age of 10 (26). Gender differences in pain-related disability is however more uncertain. One study claims that women have higher pain-related disability while two studies claim the opposite (27-29). A forth study, however, shows no difference between gender for pain-related disability (30). When gender difference has been examined for FDI it has shown that girls score higher on the test and are therefore reporting greater disability than boys (23).
Age difference in children and adolescents with pain-related disability
The prevalence of pain increases with age for children and adolescents (2). A study concerning participants with chronic low back pain showed result that also pain-related disability is affected by age and that older participants have higher disability (31). Another study, that investigate children and adolescents with recurrent headaches, also report a correlation with age and functional disability. This study, however, indicates that the children had higher disability than the adolescents in the study (32). When investigating the correlation between age and pain-related disability for FDI it has been found that the test has a weak but not significant correlation between the two variables (23).

Research question
Assessment of pain-related disability is an important factor in the evaluation and treatment of pediatric patients with chronic pain. The FDI is a well-established measurement of functional impairment among children and adolescents with pain, but concerns about the instruments sensitivity to detect low degrees of pain-related disability has been put forward. Today there is a lack of measurement for pain-related disability for children and adolescents to choose from other than FDI. Based on this need the Pain limitation List (PLL) was developed to fill this gap and aims to be used when the FDI does not fit the child. Before PLL can be implemented it has to be tested psychometrically.

Recent research claims that there is a difference in pain-related disability between gender, therefore it is a valuable domain to investigate in relation to PLL. To find the right population for the test it is essential to examine if the test fits for both genders or for example only girls. The different scales of pain for different ages indicate that pain can be estimated very different depending on how old the child is. The age-criteria for this study is 8-18 years and to determine the optimal age range for PLL the correlation between PLL and age needs to be analysed. Since PLL aims to measure pain disability it is also important to investigate how this new instrument shows correlations between pain disability and factors like age and gender differences.

Objective
The objective of this study was to examine the concurrent validity of the PLL for a clinical population of children and adolescent with chronic pain. The objective was also to investigate possible roof or floor effects for both tests, possible difference between gender in terms of
pain disability measured by PLL and FDI and the association between PLL and age, and FDI and age.

Questions
1. What is the concurrent validity between PLL and FDI in children and adolescents with pain?
2. How big is the floor and ceiling effect in PPL and in FDI in children and adolescents with chronic pain?
3. What is the difference between gender, with respect to pain disability, in PLL and in FDI, in children and adolescents with pain?
4. What is the association between age and PLL as well as age and FDI, in children and adolescents with pain?

METHOD

Design
The study was a cross-sectional study and it had a descriptive, correlational and comparative design due to the research about description of participant’s answers from two different instruments, the correlation between PLL and FDI, the correlation between age and PLL, and age and FDI, and the comparison in PLL and in FDI between boys and girls (24).

Selection
Three different out-patient clinics for children and adolescents in Uppsala were recruiting participants for the study, between March 2013 and May 2016. The selection of the participants in the study was made by a convenience sample since all children/adolescents who were asked and fit the inclusion criteria were able to participate in the study. 86 children and adolescents were included in the study.

The inclusion criteria for the study were:
- Children and adolescents between the ages 8-18 years.
- Musculoskeletal pain or tension-type headache.
- Pain that has lasted for 3 months or longer.

The exclusion criteria for the study:
- Patients with severe cognitive difficulties.
- Patients with severe psychological disease.
• Lack of knowledge of the Swedish language.

**Ethical considerations**
The study had been approved by the ethical review board in Uppsala, reference number: dnr 2013/018. The individuals who were asked to participate in the study gave their written consent before they were included in the study.

**Data collection**
The collection of data consisted of an on-line web-based survey. Demographic variables included in this study were age, gender and pain duration. Both the FDI and the PLL were included in this survey. That means the children performed both tests during the same time. 

*The FDI* contains questions about disability in sleeping and rest, eating, household chores and school, see appendix 1. The questions are rated on a 5-point Likert scale (0-4, 0= no trouble, 4 = impossible). The answers are summed up from 0 to 60 points, where higher score indicates pain-related functional disability (23). The FDI has demonstrated adequate validity and reliability and the test is a very common measurement in paediatrics (23, 33). The concurrent validity has the significance of 0,71, 0,52 and 0,53 (p< 0,001), where FDI was compared to Pennebaker Inventory of Limbic Languidness (PILL), Hopkins Symptom Checklist (HSCL), Child Behaviour Checklist externalizing behaviour (CBCL) and the variables anxiety depression and internalizing behaviour. Construct validity exists between FDI and other tests measuring physical and emotional health (CSI 0,65 + 0,47, STAI 0,47 + 0,28, CDI 0,38 + 0,29, CBCL internalizing Behaviour 0,36, 0,43). Finally, there is evidence for predictive validity (school absence 0,44 + 0,35, bed days 0,46 + 0,45, medication use 0,26 + 0,22, somatic complaints 0,45 + 0,21) and discriminant validity (26, 40 + 21,03) (21). The reliability for the test was examined by using Cronbach’s coefficient alpha for the child- and the mother-report of FDI and the coefficient was high for both reports (0,92 initial interview and 0,85 3-month follow-up for the child, 0,95 for both initial interview and 3-month follow-up for the mother) (23).

*The PLL* consists of questions in six different areas, which are; transportation (walking etc.), school, eating, activities of daily living, social activities and sleep/rest, see appendix 2. The two last questions in the instrument ask the child to describe the recreational activity that is difficult because of the pain and three things that are difficult because of the pain (reading for example). To count the points of the PLL, with a total score of 188, a scale from 0-3 is used, where 0 is “Nej inte alls” and 3 is “Ja, precis som vanligt”. The fifth answer, “gör aldrig detta
av andra skäl än smärta”, is not included in the summation. A low score of the PLL shows functional disability caused by pain.

According to the founder of PLL, the development of the test started with focus group interviews to reveal information about daily activities of children and adolescents. There were two focus groups, one with children at the ages 10-12 years and one with adolescents between 13-17 years. “What are the things you normally do on an ordinary school-day?” was the question asked to the focus group and the answers resulted in a list of activities a Swedish school student participate in a normal day. 47 items were developed based on the activities and by professional input a preliminary content and construct validity were executed. The validation resulted in modifications of the items to make them more specific regarding behaviour and location where the behaviour was performed. The last modification of the test was to split double questions into two questions and after this the test was complete.

Physicians, nurses, physiotherapists or psychologists asked their patients and their parents if the patients wanted to participate in the study. When the participants and their parents agreed to take part in the study their name, address, e-mail address and telephone number was collected and a written consent for participation in the study was obtained. Thereafter, the link to the web-based questionnaire was sent to the given e-mail address with the request of answering the questionnaire within one week. The participants got the instruction to answer the questionnaire alone. If the participant needed help with a question the parents were able to help the participant. If the participant failed to answer in one week a reminder was sent by e-mail and after a further week a research staff called to verify that the e-mail address was correct and if the participant or the parents regret the participation in the study and wanted to quit the study.

When the data collection was finished the data was delivered to the author in an excel file. The data was then analysed by using the statistical programme IBM SPSS Statistics.

**Data analysis**
To compare the FDI and the PLL the answers for each individual on both tests were summed and thereafter the sum of the two tests for each individual was compared with each other. The amount of children who used the fifth response category in PLL (“jag gör aldrig detta av andra skäl än smärta”) is presented descriptively in appendix 1.

Gender is presented as percentage, and pain duration and age is described as mean and standard deviation (SD) when data was normal distributed and median and interquartile range if not (24). Any floor or roof effect for the two tests was revealed by exploration of the
maximum or minimum score for the tests. The most common cut off of maximum or minimum score to reveal roof or floor effect is 15 %, i.e. 15 % of the participants have to perform maximum or minimum score to reveal a floor or roof effect (34). For that reason, this study use the same cut off. The Spearman correlation coefficient was calculated to evaluate the association between PLL and FDI, and Spearman was also performed to evaluate the association between age and PLL and age and FDI. This statistical test was used since it investigates correlations between two different variables when data is ordinal. To answer question 3 Mann-Whitney test was used to calculate differences between independent groups (boys and girls) when data is ordinal (24). The data had a few sporadic missing values of the FDI (2 missing values) and the PLL (4 missing values). To handle the missing data, and the fifth response category in PLL, the median of the answers in the same domain as the missing value was imputed (8). Unfortunately, the number of individuals who declined to participate in the study was not registered.

RESULT
100 participants were recruited to the study. After the completion of the survey 2 participants were excluded since the duration of their pain was too short, 5 participants due to incomplete questionnaires and 7 participants since they did not record duration of the pain. Hence, 86 participants were finally included in the analysis. The descriptive statistics is presented in table 1 and the fifth response category in PLL is presented descriptively in appendix 1.

Table 1. Description of basic variables in the study.
FDI=Functional Disability Inventory, Pain Limitation List, Md= median, IQR= interquartile range.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Female, n (%)</th>
<th>Male, n (%)</th>
<th>Age, Md (IQR)</th>
<th>Pain duration in months, Md (IQR)</th>
<th>FDI, Md (IQR)</th>
<th>PLL, Md (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%)</td>
<td>65 (76%)</td>
<td>21 (24%)</td>
<td>14 (4)</td>
<td>21 (41)</td>
<td>9,5 (14)</td>
<td>122 (36)</td>
</tr>
<tr>
<td>Male, n (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age, Md (IQR)</td>
<td>14 (4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain duration in months, Md (IQR)</td>
<td>21 (41)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FDI, Md (IQR)</td>
<td>9,5 (14)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLL, Md (IQR)</td>
<td>122 (36)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Concurrent validity between PLL and FDI**
There was a strong correlation between FDI and PLL, r=-0.740 (p<0.001) between FDI and PLL. Figure 1 shows the downward trend between PLL and FDI. Two observations in the lower left corner deviate from the pattern seen in the rest of the dataset.

![Figure 1. Scatterplot of PLL and FDI. n=86.](image1)

**Floor and ceiling effect in PLL and FDI**
There was no significant roof or floor effect in PLL and FDI. The boxplot shows that the box for FDI is lower than the box for PLL, (low scores gives low box). See figure 2 and 3 as well as table 2.

![Figure 2. Boxplot of the score for the participants in PLL. n=86.](image2)
Table 2. Highest and lowest score for participants answers in PLL and FDI. h=highest score, l=lowest score, ()=maximum or minimum score for the test.

<table>
<thead>
<tr>
<th></th>
<th>FDI h</th>
<th>FDI l</th>
<th>PLL h</th>
<th>PLL l</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>53 (60)</td>
<td>0 (0)</td>
<td>138 (188)</td>
<td>4 (0)</td>
</tr>
<tr>
<td>Frequency</td>
<td>5</td>
<td>5</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Percent</td>
<td>5,8</td>
<td>5,8</td>
<td>12,8</td>
<td>1,2</td>
</tr>
</tbody>
</table>

**Difference between gender in PLL and FDI**

There was no significant difference between gender in PLL or FDI, see table 3.

Table 3. Difference in PLL and FDI for boys and girls. Median (Md) of the answers for boys and girls for the two tests. IQR=Interquartile range. Significant level p<0.05.

<table>
<thead>
<tr>
<th></th>
<th>Boys Md (IQR)</th>
<th>Girls Md (IQR)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PLL</td>
<td>126 (38)</td>
<td>121 (36)</td>
<td>0,725</td>
</tr>
<tr>
<td>FDI</td>
<td>8 (13)</td>
<td>10 (16)</td>
<td>0,352</td>
</tr>
</tbody>
</table>

**Correlation between PLL and age and between FDI and age**

There was a weak positive correlation between FDI and age, r=0,249 (p<0,021). For PLL and age, there was a weak negative but not significant correlation r=-0,143 (p<0,191).

**DISCUSSION**
Summary of result
The study showed that there was a strong correlation between PLL and FDI and a weak correlation between FDI and age. There were no differences in gender in PLL or in FDI and no roof or floor effect could be seen in the two tests according to the 15 % cut off limit.

Discussion of result
For a test to be accepted and evidence based the test has to be reliable and valid. This study showed that PLL has concurrent validity when tested against FDI, which is a step forward to make PLL an evidence based instrument.

A floor or ceiling effect could not be seen for either PLL or FDI. However, more answers in FDI resulted in lower scores compared to PLL. This could argue for the PLL to be a more sensitive for lower pain-related disability in children and adolescents with chronic pain. Despite this, both tests tend to get low scores in some questions. The PLL was developed to decrease this phenomenon and it has improved the low scores a little. Future studies could examine if there are questions which repeatedly scores low and therefore can be excluded from the test since these questions would not contribute to the result.

A correlation between age and pain-related disability have been demonstrated in other studies (31,32). As said, one study revealed a low but significant correlation with FDI and age (35). According to the result of this study, FDI and age has a weak correlation but PLL and age lacks a correlation. However, since previous research have shown a correlation the result of this study could have been different with more participants included.

Studies have shown differences between gender with respect to pain-related disability (27-29,36). Gender-differences was also seen in pain-related disability measured with FDI (23,35). Another study, however, showed no difference in gender with respect to pain-related disability (30). This support the result of this study since no significant difference in gender could be seen. Consequently, disability is not correlated with gender differences in this study of PLL.

The incidence of chronic pain in children and adolescents is higher than previously thought (34). Therefore, the need for reliable instruments increases. It is essential to examine and start with an intervention based on the examination as soon as possible. To help the child rehabilitate the examination and intervention must be based on evidence-based practice (24). A reliable test is therefore crucial. As mentioned earlier, pain in children can cause limitation of activities and functional disability (10,11). Since PLL target and explore these fields, the instrument is of current interest and essential to understand the expression of pain in children.
Two observations in the lower left corner deviate from the pattern seen in the rest of the dataset. This seems to be incorrect since the results from the tests is conflicting. However, when looking at the data these two individuals scored low on both tests. This could be explained as a misunderstanding of the answering of the questionnaire. The two participants might not have had problems with pain-related disability, scored therefore low on FDI and thought PLL had the same ranking system as FDI, with 0=no trouble.

Discussion of method
To measure functional disability, the pain for the individual becomes more nuanced and gives the investigator a fairer insight of the individual’s problems caused by the pain. An instrument like PLL gives this prospect and the questions in the test are more adopted for this, compared to FDI. As there were only a few missing values of the two tests it seems that the participants understood the test and could answer the questions, despite the fact that PLL is a long questionnaire. 46 items in a questionnaire, as in PLL, make the test slightly harder to use clinically. Therefore, a factor analysis should have been adequate for PLL, to reduce the amount of items. However, this study focused on the validity for PLL and due to that, a factor analysis was not prioritized.

The fifth response category in PLL makes the result harder to analyse. A positive aspect to include this response in the questionnaire is that it makes it easier for the child to answer as correct as possible. If a child/adolescent don’t do an activity for other reasons than pain, it is difficult to estimate how they would have been doing the activity in respect for their pain. Therefore, the fifth response category is useful. However, the response can’t be ranked and this affect the score and the interpretation of the result. In this study, several children and adolescents used the fifth response category and therefore many digits were imputed afterwards, in the same way as missing values. Especially question 23 and 32 but also 6 differed from the answers since many participants used the fifth answer on these questions. These questions are different than the others since they are usually not included in normal daily life. For example, taking a shower in school might only happen if the children have physical education, otherwise they shower at home. For further development and utility of PLL an elimination of the fifth response, and a factor analysis for the three protruding questions, should be considered. Since FDI is a valid and reliable test it is appropriate to use the same responses in PLL as in FDI, by using a likert scale of 0-4.

There are several limitations to the current study. The sample was limited to a clinical population of children with pain duration of 3 moths or more and may not be representative of
children or adolescents with shorter pain duration. Additionally, there was no record of how many children and adolescents declining to participate in the study and their characteristics. This could all influence the generalizability of the results. Thus, future studies need to address these issues.

A limitation of this study is the examination of concurrent validity. FDI was compared to many different measurements and variables in the procedure of examine the concurrent validity for FDI (PILL, HSCL and CBCL). Due to this, FDI has a strong and trustworthy concurrent validity. Further studies should therefore examine the correlation between PLL and several tests and variables, so the new test gets a strong concurrent validity, for example pain intensity.

Ethical discussion

For a study to be approved by an ethical review board the ethic application for the study have to include consent from the superior of the care units. Since this study is part of a larger study that was approved it is not needed to append these consents in this study.

If the child/adolescent or their parents later regret their decision of taking part in the study they were allowed to do so and all information about the participant was removed from the data. The children got brief oral information about the study and the children/adolescents who wanted to participate got written information about the purpose about the study, voluntary participation and the handling of secrecy.

A study with participants consisting of children and adolescents requires different aspects of ethical considerations. The participant must be able to make independent decisions and understand the study. Therefore, it is crucial that the study is adapted to the child’s/adolescent’s level of understanding (37). This study recruited the participants from 3 different care units specialized for children and adolescents. Accordingly, the recruiters of the study were experienced care givers for children and adolescents.

To obtain written consent from a child it is important to also obtain a written consent from the parent, which this study accomplish.

Since it is different to perform a study with children compared to a study of adults it is needed to consider the ethics of a study of children and adolescents even more (37). It is crucial that the benefit of a study with children and adolescents outweighs the disadvantages to examine children and adolescents. As said earlier there is a need for measurements adopted for children that explore the functional disability of pain and therefore this study is important and make a benefit for the care of children.
The participants were instructed to answer the questionnaire alone. However, the study had a rather large age range, so there is a possibility the younger children got help from their parents to answer the questions if they didn’t understand them. This can also explain the missing values of a few questions. Nevertheless, this is just a speculation of how the participants accomplished the questionnaire.

The exclusion criteria of lack of knowledge of the Swedish language was established since the questionnaire was written in Swedish and therefore it was required that the participants understood Swedish.

**Clinical implication and future studies**

This study is the first step to make PLL evidence-based. A study that execute a factor analysis would be useful to decrease the amount of questions in PLL. As mentioned in the background there are several types of validity. Since this study only investigates the concurrent validity against one domain/measurement, i.e FDI, more studies are needed to examine other kinds of validity. Reliability is also essential to strengthen a questionnaire. To investigate this a test-retest is required. Future studies with testing of the reliability are needed. Since PLL lacks proof of reliability and several aspects of validity the test is not yet ready to be implemented in clinical practice.

**Conclusion**

This study shows that PLL has concurrent validity against FDI (r: -0.740), can be used for both sexes and ages between 8-18 years and a floor or ceiling effect could not be seen in this study. However, additional tests of validity, a factor analysis and tests for reliability are warranted. Hence, more studies are required to make PLL an accepted and reliable instrument.

**REFERENCES**


APPENDIX 1

The amount of the answer 5 in PLL for all questions and the gender distribution of the answers.

<table>
<thead>
<tr>
<th>Question</th>
<th>Total N</th>
<th>Boys/girls</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>0/2</td>
</tr>
<tr>
<td>5</td>
<td>7</td>
<td>1/6</td>
</tr>
<tr>
<td>6</td>
<td>9</td>
<td>2/7</td>
</tr>
<tr>
<td>7</td>
<td>4</td>
<td>0/4</td>
</tr>
<tr>
<td>8</td>
<td>4</td>
<td>0/4</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>12</td>
<td>4</td>
<td>0/4</td>
</tr>
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<td>13</td>
<td>2</td>
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<tr>
<td>14</td>
<td>4</td>
<td>1/3</td>
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<tr>
<td>15</td>
<td>0</td>
<td>0/0</td>
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<td>16</td>
<td>3</td>
<td>0/3</td>
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<td>17</td>
<td>3</td>
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<td>7</td>
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<td>16</td>
<td>3/13</td>
</tr>
<tr>
<td>33</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>34</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>--------</td>
<td>--------</td>
</tr>
<tr>
<td>35</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>36</td>
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<tr>
<td>37</td>
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<td>0/2</td>
</tr>
<tr>
<td>38</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>39</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>40</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>41</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>42</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>43</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>44</td>
<td>0</td>
<td>0/0</td>
</tr>
<tr>
<td>45</td>
<td>1</td>
<td>0/1</td>
</tr>
<tr>
<td>46</td>
<td>1</td>
<td>0/1</td>
</tr>
</tbody>
</table>
APPENDIX 2

The Functional Disability Inventory (FDI)

Svårigheter med dagliga aktiviteter
När man är sjuk eller inte mår bra är det ibland svårt att utföra sina vardagliga aktiviteter. Under de senaste 2 veckorna, har du på grund av smärtor haft några fysiska problem att utföra någon eller några av de aktiviteter som står nedan.

Kryssa för de alternativ som du tycker stämmer bäst för dig.

<table>
<thead>
<tr>
<th>Inga problem</th>
<th>Lite problem</th>
<th>En del problem</th>
<th>Mycket problem</th>
<th>Omöjligt</th>
</tr>
</thead>
<tbody>
<tr>
<td>At gå till badrummet.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At gå uppför trappor.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At göra något med en vän (spela spel till exempel).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At hjälpa till hemma.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At äta regelbundna måltider.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At stanna upppe hela dagen utan att vila.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At åka buss eller bil.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Kom ihåg att du tillfrågas om svårigheter som beror på din fysiska hälsa.

<table>
<thead>
<tr>
<th>Inga problem</th>
<th>Lite problem</th>
<th>En del problem</th>
<th>Mycket problem</th>
<th>Omöjligt</th>
</tr>
</thead>
<tbody>
<tr>
<td>At vara i skolan hela dagen.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At delta i aktiviteter på idrottsgymnastiken (delta i någon sport).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At läsa eller göra tavlor.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At titta på TV.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At gå cirka 100 meter.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At springa cirka 100 meter.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At gå och handla.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>At somna och sedan sova på kvällen.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
APPENDIX 3

The Pain Limitation List (PLL)

Om du har haft smärta under de två senaste veckorna skulle vi vilja att du svara på frågorna nedan. Ibland kan det vara så att man inte vill att göra något eller tycker något är tråkigt, och att man därför låter bli att göra det. I instan nedanför handlar om hur mycket olika saker i ditt liv påverkas av smärta

Även om du har haft ont de två senaste veckorna, har du ändå kunnat....

<table>
<thead>
<tr>
<th>Nej, inte alls</th>
<th>Ibland</th>
<th>Ofta</th>
<th>Ja, precis som vanligt</th>
<th>Jag gör aldrig detta av andra skäl än smärta</th>
</tr>
</thead>
<tbody>
<tr>
<td>ta dig till och från skolan på det sätt du vanligen gör?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>gå i ca 5-10 minuter?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>gå i trappor?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>springa några minuter?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>ta dig till och från friidsaktiviteter på det sätt du vanligen gör på skoldagar?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>ta dig till och från friidsaktiviteter på det sätt du vanligen gör på helgerna?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>cykla i ca 10 minuter?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Även om du har haft ont de två senaste veckorna, har du ändå kunnat....

<table>
<thead>
<tr>
<th>Nej, inte alls</th>
<th>Ibland</th>
<th>Ofta</th>
<th>Ja, precis som vanligt</th>
<th>Jag gör aldrig detta av andra skäl än smärta</th>
</tr>
</thead>
<tbody>
<tr>
<td>vara aktiv på idrotten i skolan?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>kunna koncentrera dig på lektioner?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>delta aktivt på lektioner som matte, historia, språk?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>göra läxor?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>delta aktivt under lektioner, som hemikunskap, slöjd, musik, bild?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>sitta vid datorn hemma (tex surfar/pela)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Även om du har haft ont de två senaste veckorna, har du ändå kunnat....

<table>
<thead>
<tr>
<th>Nej, inte alls</th>
<th>Ibland</th>
<th>Ofta</th>
<th>Ja, precis som vanligt</th>
<th>Jag gör aldrig detta av andra skäl än smärta</th>
</tr>
</thead>
<tbody>
<tr>
<td>åta frukost hemma en skoldag?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta frukost hemma på helgen?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta lunch i skolmatsalen?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta lunch hemma på helgen?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta middag hemma på skoldagar?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta middag hemma på helgen?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>åta hos en kompis?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Även om du har haft ont de två senaste veckorna, har du ändå kunnat....

<table>
<thead>
<tr>
<th>Nej, inte alls</th>
<th>Ibland</th>
<th>Ofta</th>
<th>Ja, precis som vanligt</th>
<th>Jag gör aldrig detta av andra skäl än smärta</th>
</tr>
</thead>
</table>

26
<table>
<thead>
<tr>
<th>Även om du har haft ont de två senaste veckorna, har du ändå kunnat...</th>
</tr>
</thead>
<tbody>
<tr>
<td>träffa kompisar hemma en skoldag?</td>
</tr>
<tr>
<td>träffa kompisar hemma på helgen?</td>
</tr>
<tr>
<td>vara/umpås med kompisar, tex på stan, på café, eller på bio?</td>
</tr>
<tr>
<td>gå på fest?</td>
</tr>
<tr>
<td>handiga gå i affärer?</td>
</tr>
<tr>
<td>titta på TV?</td>
</tr>
<tr>
<td>undgås med syskon och föräldrar?</td>
</tr>
<tr>
<td>laga mat eller hjälpa till med matlagning?</td>
</tr>
<tr>
<td>plocka undan efter matens/diskan?</td>
</tr>
<tr>
<td>städ ditt rum?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Även om du har haft ont de två senaste veckorna, har du ändå kunnat...</th>
</tr>
</thead>
<tbody>
<tr>
<td>komma upp ur sangen på morgonen en skoldag?</td>
</tr>
<tr>
<td>komma upp ur sangen på morgonen en helgdag?</td>
</tr>
<tr>
<td>gå och lägga sig på kväljen en skoldag?</td>
</tr>
<tr>
<td>gå och lägga sig på kväljen på helgen?</td>
</tr>
<tr>
<td>vara uppe hela dagen utan att vila en skoldag?</td>
</tr>
<tr>
<td>vara uppe hela dagen utan att vila på helgen?</td>
</tr>
<tr>
<td>sova på skolbudarna?</td>
</tr>
<tr>
<td>sova på helgetna?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Även om du har haft ont de två senaste veckorna, har du ändå kunnat...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vara med fullt ut i dina vanliga fritidsaktiviteter (som är.....Fyll i i rutan nedan)?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nej, inte alls</th>
<th>Ibland</th>
<th>Ofta</th>
<th>Ja, precis som vanligt</th>
<th>Jag gör ärligt detta av andra skal än smärta</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nej, inte alls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nej, inte alls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nej, inte alls</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Skriv in den fritidsaktivitet du har svårt med pga smärtan

Finns det andra saker som du har haft svårt att göra för att du har haft ont de senaste två veckorna?

i rutan nedan: skriv minst tre saker som du haft svårt att göra på grund av din smärta tex läsa, simma eller spela innebandy.

300 tecken kvar

Får forskarna i studien höra av sig till dig om de undrar över något? *

☐ Ja
☐ Nej