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What are important consequences in children with spinal pain? A qualitative case study of Danish 9-12-year olds.

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ABSTRACT

Objectives

It is currently unknown whether children, adolescents and adults experiencing spinal pain are affected by their pain in a similar manner. Thus, it is also unclear whether questionnaires developed for adults, can simply be transferred to paediatric populations. The objective of this study was to explore the physical, psychological and social consequences of a life with spinal pain among Danish children and to compare these consequences with the content of common adult questionnaires.

Design and setting

A qualitative case study based on interviews and focus group discussions with participants recruited from two public schools in different regions of Denmark.

Participants

Thirty-six children aged 9 to 12 with spinal pain were invited to an interview using age, pain intensity and frequency, and general well-being status as inclusion criteria. Nineteen (9 girls and 10 boys) accepted to participate.

Methods

Data were transcribed verbatim and coded by following a thematic approach to elicit key concepts relevant to spinal pain. Subsequently, confirmatory focus group interviews were conducted, and all codes were assigned categories corresponding to the International Classification of Function, Disability and Health (ICF) for comparison to adult questionnaires.

Results

Nineteen interviews were included, and 21 individual codes identified. Across the codes, five themes emerged in relation to children's experiences of living with spinal pain: 'Sports and play', 'Axial loading', 'Coping strategies', 'Mood changes', and 'Pain anxiety'. Codes and themes were confirmed by the focus groups. Only approximately 40% of the identified ICF categories were covered by adult spinal questionnaires.

Conclusions

The negative impact of spinal pain on 9-12-year olds pivots around five themes with 'sport and play' and 'axial loading', corresponding well with physical function in adults. However, the individual codes differed

1
2 considerably, and a new questionnaire should therefore be age-specific and include the identified codes
3
4 within each theme.
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8 **Strength and limitations of this study** 9

- 10 • The first qualitative study on children with focuses on important consequences of spinal pain at the
11 age of 9-12
12
- 13 • Findings are based on interviews of children who had experienced non-trivial spinal pain
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- 15 • The results were confirmed by focus group discussion
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- 17 • The results may not generalisable beyond a Scandinavian context
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INTRODUCTION

Spinal pain is common and costly among adults, and in addition to the impact on an individual level, the high prevalence of back pain is a serious socioeconomic challenge to society.^{1 2} The impact of spinal pain in children is uncertain, but the costs of chronic pain in adolescence has been estimated to 19,5 bil. US dollars in the US, which exceeds asthma, ADHD and obesity.³ Prevalence rates increase with age, until reaching the same level as in adults around the age of 18.^{4 5} Furthermore, evidence suggests that back pain early in life significantly increases the risk of back pain in adulthood.⁴ Thus, childhood and early adolescence might represent critical time periods for the improvement of lifetime trajectories of back pain.

Despite the increasing interest in spinal pain in children and adolescents, our knowledge about their experiences, challenges and limitations due to back pain remains inadequate.⁶ Most of our knowledge pertains to adults where a plethora of questionnaires have been developed and validated to assess function and limitations in back pain,⁷ but no such questionnaires exist for children with spinal pain. Adults report a broad variety of consequences of non-specific back pain,^{7 8} including mental and social constrains, as well as physical limitations in everyday life, reduced working ability and various forms of mental, cognitive and social stress.⁸ It is currently unknown whether children and adolescents experiencing spinal pain are affected in a similar manner as adults and therefore, it is unclear whether questionnaires, developed for adult populations, can simply be transferred to younger populations. Given the fact that children's cognitive levels, everyday lives and social relationships are often very different from those of adults,⁹ unique domains might be important for children. Furthermore, even if outcome domains for adults seem transferrable to children, it is plausible that some specific items may not be suitable in a paediatric context. Obvious examples include cleaning, work and sexual function.⁸

Current paediatric-specific pain questionnaires focus on general pain or pain related to specific diagnoses such as cancer, rheumatic disease or abdominal pain.¹⁰⁻¹² To our knowledge, only one questionnaire investigating impairment due to paediatric back pain exists (The Paediatric Back Outcome Measure), and this is intended for use in an a narrowly defined athletic context.¹³ Therefore, an argument exists for the development of more generalistic questionnaires. In response we have initiated a research programme to develop a series of questionnaires measuring consequences of musculoskeletal problems in children; the first

1
2 questionnaire relating to spinal pain. Prior to the development of a questionnaire, qualitative studies are
3
4 essential for a clear conceptualization of the target construct.¹⁴ This is essential to establish formal content
5
6 validity, because it is during this process that the domains (target constructs) are identified.
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8
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10 The present study represents the first step in the development of a paediatric questionnaire focusing on the
11
12 consequences of spinal pain. The objective is to 1) identify key domain-related concepts relevant to spinal
13
14 pain of 9-12-year-old children by exploring their own experiences of the physical, psychological and social
15
16 consequences of spinal pain, and 2) to compare these concepts to the content of commonly used adult low
17
18 back and neck pain questionnaires.
19

20 21 22 **METHODS AND MATERIAL**

23 24 **Design**

25
26 A qualitative case study using an inductive approach was deemed appropriate to investigate and understand
27
28 how children experience the consequences of spinal pain. The design focused on the individual child's
29
30 cognitive level and experiences from daily life.⁹ To confirm the findings, this was followed by focus group
31
32 interviews. Results were transformed using the International Classification of Function, Disability and
33
34 Health (ICF) coding system to enable comparison to commonly used adult questionnaires investigating
35
36 spinal pain.
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40 We approached this topic from a constructivist perspective, in that the researcher attempted to co-create
41
42 meaning with children with regard to the expression of their lived experiences.¹⁵
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48 49 **Identification of key concepts**

50 51 **Sampling strategy**

52 We developed a purposive sampling strategy in which we sought to interview Danish schoolchildren in the
53
54 age group 9-12 years with troublesome spinal pain.¹⁶ Previous studies noted discrepancies between
55
56 children's and parents' reports, when it comes to the child's experience of pain.¹⁷ Therefore, it was decided
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58 not to use the parents as a proxy measure, and data was collected directly from children, creating an inside
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1
2 perspective.⁹ Sample size was not determined a priori but interviews were conducted until data saturation in
3
4 each age band and well-being strata was reached.
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8 Participants

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10 All participants were recruited from two Danish public schools in two different regions of the country and
11 children with spinal pain between the ages of 9 and 12 were included. The lower age limit was set to ensure
12 the children's cognitive and linguistic ability to understand and reflect on themselves.¹⁸ The upper age limit
13 was set to include children before they become too affected by puberty, as research has shown that puberty,
14 and especially the growth spurt (boys around 14 years, girls about 12 years), is associated with increased
15 incidence of spinal pain.¹⁹
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25 A booklet containing The Young Spine Questionnaire (YSQ)²⁰ and the Kid-Screen 10²¹ was administered to
26 identify children suffering from spinal pain and their level of mental well-being. The latter was included as it
27 is unknown whether a child's mental well-being influences the experience of spinal pain. We categorized the
28 children's well-being into three groups following the instruction and the predefined groups (low, normal and
29 high level of well-being) from the Kid-Screen Group.²¹
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38 The interviewees were selected from the group of children who fulfilled the inclusion criteria listed in Table
39 1. All eligible children were divided into the three levels of well-being, and interviewees were randomly
40 drawn from the three groups to optimize equal distribution of the well-being strata.
41
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46 --- Table 1 ---

47 Pilot procedures

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49 To ensure that all procedures were suitable for the study, these were tested in a pilot test conducted at a
50 Danish public school on the island of Funen and included four children, one of each age band (9-12 years)
51 and representing both sexes as well as all three well-being groups.
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Data collection

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2 Information material was distributed to the teachers, children and their parents. The YSQ²⁰ and the Kid-
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4 Screen 10²¹ questionnaires were handed out to all pupils in the 3rd to 6th grade at the two participating
5
6 schools.
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10 Parents to the children selected for interviews received additional information and returned informed
11
12 consent. Before conducting each interview, the answers on the YSQ were examined by the interviewer.
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15

16
17 One of the authors (ABS) conducted all interviews from January 2017 to March 2017 within a week after the
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19 child had completed the questionnaires. The face-to-face approach was chosen to meet the children's level of
20
21 understanding and to get the best cooperation with the children. A full body drawing, and the revised faces
22
23 pain scale (rFPS)²² were used to aid the children expressing themselves, as it has been found that children
24
25 aged 5 years or older are able to provide meaningful self-reports if they are provided with age appropriate
26
27 tools.²³ All interviews were carried out at the participants' schools during normal school hours.
28
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30

31
32 The interviews were semi-structured and followed a bio-psycho-social framework to ensure that all aspects
33
34 of the children's lives were covered. Participants were told that they were free to terminate the interview at
35
36 any time. The interview guide was structured into two sections: 'Getting to know the child better', and
37
38 'Talking about the back'. A maximum of two interviews were carried out per day, and all interviews were
39
40 recorded and transcribed for analysis prior to conducting further interviews. As the interviews were carried
41
42 out with children less than 12 years of age, a member check was not considered appropriate.
43
44
45

46 Data analysis

47
48 The transcription and coding were carried out inductively by one of the authors (ABS) to facilitate the
49
50 emergence of general themes of key concepts relevant to spinal pain. Themes relating to children's
51
52 experience of spinal pain and the consequences thereof were then identified across the codes. The process of
53
54 the data collection and analysis is shown in Figure 1.
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58

59 ---- Figure 1 ----
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1
2 Coding and analysis were carried out using the Atlas Ti computer assisted qualitative data analysis software
3
4 package version 1.0.49, and data were treated confidentially and anonymized in connection with the
5
6 transcription.
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10 **Confirmatory procedure**

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12 To ensure that all relevant codes were covered, and that the researchers' perception of the codes reflected the
13
14 children's own understanding, a further focused exploration of the identified codes was performed as best
15
16 practice dictates.²⁴ The express purpose was to ensure that respondents consistently include and exclude the
17
18 same features of the construct. This process required significantly more prompting from the investigators and
19
20 was therefore best accomplished through focus group interviews. These were conducted by three of the
21
22 authors (ABS, HHL and LH) on the largest of the two schools.
23
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27 **Participants**

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29 Based on the questionnaires from the first part of the study, four children, who had not been interviewed
30
31 previously, were selected from each grade (3rd-6th) based on the criteria in Table 1. New information
32
33 material and parental consent forms were distributed, inviting the children to a focus group discussion at the
34
35 school.
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40 **Data collection**

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42 Children with signed informed consent were gathered for a three-hour session at the school. First, the
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44 children received small cards with all the codes identified in the first part of the study. They were asked to
45
46 sort the cards into two piles: one with relevant and one with irrelevant statements in relation to their
47
48 experience of spinal pain. This was done individually followed by a break, allowing the researchers to note
49
50 the results. Following this, all the codes were discussed by the whole group with the researchers initiating the
51
52 discussion and probing for new codes to emerge. Next, the themes which emerged through the analysis of
53
54 the previous interviews were presented and explained to the children, followed by discussions about the
55
56 possible theme-categorizations of each code. Finally, A3 posters reflecting each theme with drawings and
57
58 words, were placed on the wall and the children placed their cards with relevant codes on the poster they
59
60 considered to be best fitting.

Comparison to adult questionnaires

All the identified codes were assigned corresponding categories using the ICF for comparison with commonly used questionnaires designed for adults. The ICF framework was chosen because it allows direct comparison between questionnaires by assigning codes from the framework to individual items, indicating similarity of content²⁵. Two researchers (LH and HHL) assigned ICF categories independently to each code using the linking rules defined by Cieza et al.^{26 27} Findings were compared, and a consensus-based process was implemented. In case of disagreement, an external expert on the ICF was consulted.

Our ICF categories were compared to the content of questionnaires commonly used to assess the consequences of low back pain (LBP) and neck pain (NP) in adults to elucidate whether the content of adult questionnaires would cover what children consider relevant.

We chose to compare our codes to two low back specific questionnaires: the Oswestry Disability Index, and the 24-item Roland-Morris Disability Questionnaire,²⁸ and three neck specific questionnaires: The Neck Disability Index, the Neck Bournemouth Questionnaire, and the Neck Pain and Disability Scale.²⁹ ICF categories for each questionnaire were derived from published literature.²⁹⁻³²

Patient and public involvement

The public was not involved in the design, conduct, reporting, or dissemination of this study.

Ethical approval

The study was approved by the Danish Data Protection Agency (J.nr. 2015-57-0008) but approval was not required from the local ethics committee according to Danish law.³³

RESULTS

Identification of key concepts

Pilot procedure

1
2 No methodological changes were necessitated as a result of piloting. Data from the pilot procedure were not
3
4 included in main analyses.
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8 Participants

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10 In the two schools combined, 338 children completed the YSQ and the Kid-Screen 10, and 199 of these
11 fulfilled all inclusion criteria (41%). Thirty-six children were invited for interviews and a total of 20
12 interviews were conducted (one interview was excluded due to the exclusion criterion ‘musculoskeletal
13 diagnosis’). Nine girls and ten boys from 9-12 years spread across the three well-being strata were included.
14
15 The characteristics of the interviewees are shown in Table 2.
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20 ---- Table 2 ----

21 Data collection and saturation

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26 The interviews lasted from 15 to 30 minutes, and no participants chose to terminate the interview. Data
27 saturation was achieved at interview number 16. To investigate a potential geographic variation, interviews
28 17-19 were conducted at a school in another region of Denmark, but no new aspects came up. No noteworthy
29 differences were found between ages, gender, geographic location or well-being levels, and no re-interviews
30 were necessary.
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40 Codes and emerging themes

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42 A total of 21 individual codes were created and examples of key quotes for each code can be seen Table 3.
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44 The references are shown as ‘#Y:Z’ where Y refers to the individual and Z to the quote number.
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50 ---- Table 3 ----

51
52 Across the 21 codes, five themes emerged in relation to the children’s experiences of living with spinal pain.
53
54 The five themes were: ‘Sports and play’, ‘Axial loading’, ‘Coping strategies’, ‘Mood changes’ and ‘Pain
55 anxiety’. Table 4 provides an overview of the thematic analysis, and the codes represented in the five
56
57 themes.
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---- Table 4 ----

Each of the five themes are presented and described in detail below with examples of quotes noted in parentheses.

Sports and play

Physical limitations, such as staying away from sports or not being able to play with friends were one of the main complaints for the children (#17:2). In general, the children reported frustration and concern when they were unable to participate in sports and activities at the same level as their friends (#8:5). Some of the children tried to find a way to participate, either by communicating their pain (#3:47), or by finding another role in the game which was less physically demanding (#10:6). Some children would isolate themselves or find alternative solutions, e.g. by playing with another group of children engaging in less physically demanding games or sports (#5:73).

Axial loading

Axial loading was reported to be a risk factor for developing as well as maintaining spinal pain. Jumping on a trampoline was stated as a triggering cause of pain by a significant number of the interviewees (#7:13). Many reported that they felt unable to jump on the trampoline as it increased their spinal pain (#7:8). Walking with a heavy school bag (#4:15), playing computer games (#5:50), or sitting down in school (#9:2) were reported as other causes for an increase in spinal pain. It was also reported that the ability to concentrate was affected by spinal pain, when sitting down for longer periods e.g. in school (#9:2).

Coping strategies

Many children tried to find a logical explanation for the cause of their pain experience (#13:16) to understand or cope with their limitations and frustrations. A group of children reported that they didn't know how to get pain relief (#18:6). This contrasted with a larger group of the children, who tried to help themselves either actively or passively. Examples of active distraction strategies were playing with friends (#5:44), doing sports (#2:22), going to school (#19:22), exercises (#12:18) or stretching the back (#15:18). Examples of passive strategies to reduce spinal pain could be lying down (#13:27), restricting movements or

1
2 avoiding specific movements (#5:54), indicating a certain movement anxiety. A group of children even
3
4 reported that they were extremely aware of what they carried on their backs, e.g. heavy school bags (#2:107).
5
6 A cognitive approach was reported by some children whereby they tried to focus on something else to make
7
8 the pain disappear (#11:30). A couple of the children even said that they would hurt themselves e.g. by
9
10 pressing a hand to the back to reduce the spinal pain (#2:87). In general, the children reported less pain when
11
12 they were distracted by physical, psychological or social inputs.
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16
17 Some of the children were afraid of being misunderstood and therefore talked about their spinal pain
18
19 primarily with people who had themselves suffered from spinal pain (#10:3). The children most frequently
20
21 reported that they talk primarily with their parents (#19:14), and secondarily with friends (#10:3) or sports
22
23 coaches (#17:14) about their spinal pain.
24
25

26 27 *Mood changes*

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29 Nearly all children indicated frustration and incomprehension about their spinal pain (#5:61). A large group
30
31 of children expressed a relation between their mood and the spinal pain, especially feeling sad and frustrated
32
33 due to pain (#3:48). Some children also implied that their negative mood was caused by lack of sleep, and
34
35 that reduced sleep was due to excessive back pain (#3:48). A few reported difficulties concentrating when
36
37 experiencing spinal pain (#19:12). Although a good mood could reduce the pain, the children often
38
39 continued to feel the pain, and some were even afraid to show it in class or to teammates (#2:79).
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44 45 *Pain anxiety*

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47 A group of children reported no problems related to their spinal pain. There was some indication that they
48
49 coped with the pain as if it was a cold or stomachache, which would go away by itself (#15:23). However,
50
51 another group of children articulated some level of concern when experiencing spinal pain. There was a large
52
53 variation in how often, how much and which aspects concerned the children. Some worried that they could
54
55 not keep up with school work and that absence would influence their future lives (#10:30), while others
56
57 feared they would get the same physical limitation as they knew from their parents (#5:62). Some children
58
59 were extremely worried and reported that they could hardly cope due to the pain intensity combined with
60
their thoughts and concerns about the pain (#7:20). The children who were concerned indicated that they

1
2 were more careful regarding their backs, even when not experiencing spinal pain (#19:19). Some of the
3
4 children were even afraid to become isolated from their friends if they told them about the pain (#2:97).
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8 Group differences

9
10 A comparison of the emerging themes across age groups, gender and well-being did not reveal any
11
12 differences among the groups.
13
14
15

16 Salient issues

17
18 Two issues were not included as codes in Table 3, since they did not describe consequences of pain. ‘No
19
20 limitations’ represented children that were not affected or limited by spinal pain in everyday life despite
21
22 fulfilling the inclusion criteria for spinal pain, and ‘Cause not known’ was important to some children but
23
24 has not been explored further in this study because it refers to aetiology.
25
26
27

28
29 The analysis also identified four codes which described the area of consequences with the most impact on
30
31 the child (i.e. movement, pain, psychological factors and social limitations). Each code commenced with
32
33 ‘Worst is...’ and arose from specific questioning and were therefore not assigned to a specific theme.
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35
36

37 Confirmatory procedure

38
39 Sixteen children participated in the focus group with all four grades represented (3rd – 6th). All the
40
41 previously identified codes were chosen by at least two children as being relevant, with nine of the 21 codes
42
43 being chosen by five or more participants. It was possible to make all the children participate in the follow-
44
45 up discussion, but despite a long and lively discussion, no new codes emerged. There was a large uncertainty
46
47 among the children about categorizing the codes into themes, reflecting that some codes are represented in
48
49 more than one theme.
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53 Comparison to adult questionnaires

54
55 Of the 21 identified codes, five were classified into the ‘Body functions’ component (one shared with the
56
57 ‘Personal factors’ component), eight into the ‘Activities and participation’ component (one shared with the
58
59 ‘Body structures’ component), one as an ‘Environmental factor’, and four as ‘Personal factors’. Five codes
60

1
2 were not classifiable, whereof four related to the specific question: 'What is worst?' (codes 18-21). Some
3
4 codes could be assigned more than one ICF category, and therefore the final number of ICF categories was
5
6 24. According to the categorization rules by Cieza et al., ICF category b280 (sensation of pain) should have
7
8 been used for several of the codes. However, 'sensation of pain' is indirectly related to all the codes, since
9
10 they refer to spinal pain, and therefore we chose only to use b280 for 'pain intensity', which is a direct
11
12 expression of the pain sensation.^{26,27} The ICF categories have been added to Table 3.
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16
17 The items in the adult questionnaires were categorized within the ICF components of 'Body functions', and
18
19 'Activities and participation', whereas 'Personal factors', which the children found very important, were not
20
21 covered (Table 5). A total of 10 out of 24 ICF categories (42%) were covered by at least one adult LBP
22
23 questionnaire whereas nine (38%) were covered by adult NP questionnaires. Three categories in 'Body
24
25 functions' (sleep, emotional function, and sensation of pain) and two in 'Activities and participation' (lifting
26
27 and carrying, and sports) were included in most questionnaires whereas 11 ICF categories were not included
28
29 in any of the five adult questionnaires (one in 'Body functions', five in 'Activities and participation', one in
30
31 'Environmental factors', three 'Personal factors' and one 'not classifiable').
32
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36
37 The content of the children's codes and the content of the adult questionnaire items within each ICF category
38
39 differed considerably at times. For example, the ICF category of 'Play' (d9200) related to a physical
40
41 limitation in the children (e.g. staying at home, not being able to do the same activities as one's peers)
42
43 whereas it related to restrictions in recreational activities (i.e. 'Reading', item 4 in the Neck Disability Index;
44
45 'Family activities', item 3 in the Neck Bournemouth Questionnaire; 'Interference with social activities', item
46
47 8 in the Neck Pain and Disability Scale) in the adult questionnaire items.
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---- Table 5 ----

DISCUSSION

Precise conceptualization of a target construct is critical to the validity cascade, but also ultimately the application of a questionnaire.³⁴ Therefore, the key contribution of this investigation lies arguably in the identification of the constructs of spinal pain which are important to a 9-12-year old population. It has

1
2 previously been reasoned and observed that a poorly conceptualized target construct will inevitably result in
3 measurement error.^{14,24} As such, it was the express objective in this investigation to elicit detailed
4 descriptions of spinal pain experiences from a group of 9-12-year old children resembling the population a
5 future instrument will be applied to.
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10
11
12 The interviews revealed 21 codes, of which 17 could be classified into five themes: 'Sports and play', 'Axial
13 loading', 'Coping strategies', 'Mood changes' and 'Pain anxiety'. Several codes were represented in more
14 than one theme, and by allowing our respondents to simply 'think aloud' about their problem,²⁴ we observed
15 the physical experience in the 'sport and play' theme as the dominant cognitive hub through which this
16 group of children access and link the psychological and social domains. We also observed that the anxiety at
17 times could appear counterproductive and possibly add to a negative trajectory of pain. We therefore
18 recommend that this is addressed explicitly in future programmes for treatment and prevention of spinal pain
19 in children.
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31 Two issues were not included in the identified codes, although appearing several times. The first was 'no
32 limitation', demonstrating the important fact that some children do not experience any limitations at all,
33 despite fulfilling the inclusion criteria of spinal pain 'sometimes or often' and three or more on the rFPS.
34 This could indicate that some children are capable of handling pain of moderate intensity and frequency
35 without it causing any physical or psychosocial limitations. Another reason could relate to uncertainty
36 regarding the validity of self-reported pain in children³⁵. The other issue was 'cause not known' reflecting
37 the children's desire to know why they had pain. This was excluded as it refers to aetiology of the pain. It
38 did, however, reflect a strong desire among the children to understand their pain, although the interviewer
39 attempted to focus on the consequences of it. This desire was also obvious during group discussions and may
40 partly explain the prominent pain anxiety experienced by the children.
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54 The study also revealed four areas of impact as a result of the spinal pain. These arose from direct
55 questioning ('What is worst?') and were limitations in movement, pain, psychological factors and social
56 limitations. Distinction between these areas are important from a clinical point of view as enquiring about
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2 them have the potential for the clinician to direct treatment, or anxiety-reducing advice and support, to a
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4 specific domain.
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8 When comparing the identified codes to the content in adult questionnaires, only approximately 40% of the
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10 ICF categories were covered and this related mainly to the component of ‘physical functioning’ which is
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12 recommended as a core outcome for adults with low back pain.⁸ Psychological and social factors were much
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14 more prominent to the lived life of children and pain anxiety was a dominant theme with many children
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16 expressing fear of future pain. Therefore, it appears clear, that questionnaires developed for adults are not
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18 adequate for paediatric populations.
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23 **Strength and limitations**

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25 This is the first study using a qualitative approach to explore the consequences of non-trivial spinal pain in
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27 children aged 9-12. We believe our study findings are transferrable to settings with a similar school structure
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29 and sociodemographic composition, typically the Scandinavian countries, as we were able to reproduce the
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31 results in the confirmatory procedure. However, we advise caution using the results beyond children aged 9-
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33 12 as the experienced consequences may differ substantially in younger or older children. Furthermore, the
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35 results may not be generalisable beyond the Scandinavian culture as pain narratives may be influenced by
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37 socio-cultural factors.³⁶
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42 **CONCLUSION**

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44 For some children – although not all – spinal pain has a cascade of negative consequences, affecting their
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46 everyday life. The essential themes that emerged through the interviews with the children were restrictions of
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48 ‘sports and play’, ‘axial loading’, ‘coping strategies’, ‘mood changes’ and ‘pain anxiety’. The themes of
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50 ‘sport and play’ and ‘axial loading’ correspond well with the component of ‘physical function’ which is
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52 recommended for the adult populations, but the individual codes differ significantly. Our results confirmed
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54 that the spinal pain experience is very complex, and it is therefore essential to acknowledge that development
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56 of new questionnaires should be age-specific and include all the identified codes.
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Competing interests

The authors declare that they have no competing interests.

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Author contributions

HHL and LH conceived the study and AS, HHL, CM and LH participated in the design and coordination of it. AS carried out the interviews and the coding of the material, and HHL, AS and LH carried out the confirmatory study. HHL and LH performed the coding and comparison to the adult questionnaires. HHL, AS, CM and LH drafted the manuscript and all authors read and approved the final manuscript.

Availability of data and materials

Data are not available due to legal (GDPR) and ethical restrictions.

Tables

Table 1. Inclusion and exclusion criteria.

Inclusion criteria
<ul style="list-style-type: none"> • Children 9-12 years of age with non-specific pain in one or more parts of the spine • A pain intensity of at least face number three on the revised Faces Pain scale in the YSQ* • Children indicating having spinal pain 'sometimes' or 'often' in the YSQ • Written permission to participate in the project from a parent/guardian
Exclusion criteria
<ul style="list-style-type: none"> • Children who do not understand or speak Danish • Children with diagnosed musculoskeletal disorders

* YSQ, Young Spine Questionnaire

Table 2. The distribution of all participants according to age, gender and well-being.

	Well-being	9 years	10 years	11 years	12 years	13 years	Total
Girls spinal pain \geq 2 rFPS	Low	6 (0)	10 (0)	6 (0)	2 (1)	0 (0)	24 (1)
	Normal	14 (1)	23 (1)	18 (2)	16 (2)	9 (0)	80 (6)
	High	2 (0)	1 (1)	0 (0)	3 (1)	0 (0)	6 (2)
Boys spinal pain \geq 2 rFPS	Low	3 (1)	5 (0)	3 (1)	1 (0)	0 (0)	12 (2)
	Normal	10 (0)	15 (2)	17 (4)	12 (2)	8 (0)	62 (8)
	High	0 (0)	1 (0)	1 (0)	13 (1)	0 (0)	15 (1)
Total spinal pain \geq 2 rFPS		35 (2)	55 (4)	45 (7)	47 (7)	17 (0)	199 (20)

Note: Shows the distribution of eligible participants with spinal pain equal to or more than 2 on the rFPS, who also reported spinal pain 'sometimes' or 'often' stratified according to their well-being. The number in () is the number of participating interviewees.
rFPS, revised Faces Pain Scale

Table 3. Codes, key quotations and corresponding ICF categories

Codes	Key quotations	Reference	ICF category
Body functions			
1. Affected sleep	'I remember having difficulties falling asleep, as I could not lie down properly. I had to fall asleep as fast as possible, in order not to feel the pain when I turned, as that woke me up, (I: Have you tried waking up due to pain?) Yes.'	#19:4	b134
2. Worrying about spinal pain	'Well, I'm afraid I can't do the same things as other children, and then I can't play with them. It is also really difficult to bicycle home and everything ...'	#1:55	b152
3. Pain intensity	'... It just stops like, I almost can't breathe ...'	#5:55	b280
4. Difficulties to define the pain*	'... One night, I was just about to go to bed, my mom asked if I was feeling alright, I told her that my back really hurt. She then said I should see a chiropractor. ... It was hard to find out where it hurt so much, which was really annoying as I could not tell my mom, or the chiropractor.'	#19:7	b280 b780 pf
Activities and participation			

5. Talking with parents	‘Yes, I talked with them as I had to, and you should know that you need to be talked with...because it helps. It helped me a lot to talk with my parents about the pain’	#19:14	d350 d7601
6. Talking with friends	‘Sometimes, I tell that I have pain in my back, so I can’t play too wildly ...’	#7:23	d350 d7500 d7504
7. Do not want to talk with others about the pain	‘... I have not talked with them ... I just wanted to keep it to myself as I thought it could be really uncomfortable if other people knew that I have back pain. ... It is just something one have, and they don’t like to let other people know ...’	#19:15	d350 d710
8. Maintaining static postures	‘... You sit down for many hours and when standing up or move a bit, it starts hurting really really bad ...’	#10:17	d4150 d4153 d4154 d4155
9. Spinal load	‘.. it also hurts when I carry my bag, and the pain increases... (I: Is there a difference in carrying light and heavy stuff?) Yes, often if I have to carry a heavy bag, which gives me a headache ‘	#7:2	d430
10. Social limitation	‘Sometimes when I am asked if I can play, I say no, I just want to go home and rest. I don’t say that I have back pain, I just say I think that I want to go home and rest.’	#5:66	d750
11. Physical limitation**	‘... I can’t do the same activities, e.g. running, as the boys,...’	#3:44	d9200 d9201 d9205 b7
12. Reduction in participation	‘... I have had to stay home because I almost couldn’t stand up ...’	#10:12	d9200 d9201 d9205
Environmental factors			
13. Treatment tried/not tried	‘Yes, a lot. Often I go to my mom’s chiropractor, as he puts anything in place, and stuff like that.’ ‘No, not really. My mom tried to give me massage when I came home from handball as she knows where it hurts, because she is a nurse and have worked at a hospital.’	#9:8 #10:15	e580
Personal factors			
14. Improving factors	‘We have put less in my bag, so I only have to carry the most necessary stuff, and not even a pencil more (I: Can you feel that it helps?) Yes, it helps me, because the bag is less heavy than before, and I have less pain...’	#2:107	pf
15. Worsening factors	‘... I will not run as much as I normally do. (I: Why not?) as I can feel that it starts to hurt more.’	#14:1	pf
16. Strategies to avoid pain	‘When I sit down, then I first have to sit on my hands, as this somehow reduces the pain. I will then let go, which soothes the pain somewhat.’	#10:20	pf

Not classifiable			
17. Cause of pain known/unknown	‘It will hurt in my back, if I jump too much on the trampoline.’	#7:8	nc
	‘I actually don’t think I know why I had pain. Maybe it was because I had just made a wrong movement, or something with my neck while sleeping or something. I don’t really know.’	#17:4	
18. Worst is movement	‘The very worst, I think the worst, is to jump rope ... because I have to jump up and down, up and down.’	#3:54	nc
19. Worst is pain	‘It just hurts really bad - I can’t even go to the toilet, even though I have to (I: Is that because it hurts to walking to the toilet?) [Participant nodding].’	#1:17	nc
20. Worst is psychological factors	‘I think it is the feeling you have in the back, as it can make a bad day worse.’	#15:21	nc
21. Worst is social limitation	‘It must be that I am unable to do the same as all of my friends – that must be the worst as I feel a bit left out.’	#10:16	nc

Note: pf, personal factor; nc, not classifiable

* The code ‘Difficulties to define the pain’ appears once but has been classified as both ‘Body functions’ and ‘Personal factors’.

** The code ‘Physical limitation’ appears once but has been classified under ‘Activities and participation’ and ‘Body functions’.

Table 4. Thematic analysis.

Themes	Codes
‘Sports and play’	Pain intensity (b) Worrying about spinal pain (b) Physical limitation (d, s) Reduction in participation (d) Talking with friends (d) Social limitation (d) Strategies to avoid pain (pf)
‘Axial loading’	Pain intensity (b) Spinal load (d) Maintaining static postures (d) Social limitation (d) Cause of pain known/unknown (nc) Worsening factors (nc)
‘Coping strategies’	Difficulties to define the pain (b) Worrying about spinal pain (b) Physical limitation (d, s) Talking with parents (d) Talking with friends (d) Do not want to talk with others about the pain (d) Spinal load (d) Social limitation (d) Reduction in participation (d) Improving factors (pf) Strategies to avoid pain (pf) Treatment tried/not tried (e)

	Cause of pain known/unknown (nc) Worsening factors (pf)
'Mood changes'	Affected sleep (b) Worrying about spinal pain (b) Talking with parents (d) Social limitation (d) Improving factors (pf)
'Pain anxiety'	Worrying about spinal pain (b) Physical limitation (d, s)

Note: The four codes 'Worst is...' are not included in the themes as they arose from a specific question. Some of the codes appears in several of the themes. The main ICF component are in (): b, 'Body function'; d, 'Activities and participation'; e, 'Environmental factors'; s, 'Body structure'; pf, 'Personal factors'; nc, 'Not classifiable'.

Table 5. Comparison of ICF categories found in children aged 9-12 to what is covered in commonly used adult low back and neck pain questionnaires.

Category	ICF Description	Low back pain questionnaires		Neck pain questionnaires		
		ODI ^{30 31}	RMDQ ³⁰	NDI ^{29 32}	NBQ ^{29 32}	NPDS ^{29 32}
Body functions						
b134	Sleep function	+	+	+		+
b152	Emotional function	+	+		+	+
b280	Sensation of pain	+	+	+	+	+
b7	Neuromusculoskeletal and movement-related functions					(+)
b780	Sensations related to muscles and movement functions					
Activities and participation						
d350	Conversation					
d430	Lifting and carrying objects	+	+	+	+	
d710	Basic interpersonal interactions					
d750	Informal social relationships	+				+
d4150	Maintaining a lying position	+				
d4153	Maintaining a sitting position	+	+			
d4154	Maintaining a standing position	+	+			
d4155	Maintaining head position					
d7500	Informal relationships with friends					
d7504	Informal relationships with peers					
d7601	Child-parent relationships					
d9200	Play			(+)	(+)	(+)
d9201	Sports	+		(+)	(+)	(+)
d9205	Socialising	+			(+)	+
Environmental factors						
e580	Health services, systems and policies					
Other*						
pf	Improving factors					
pf	Worsening factors					
pf	Strategies to avoid pain					
nc	Cause of pain known/unknown					

Note: As Wang (2012) and Wiitavaara (2018) both include the ODI, the ICF classifications have been combined to include all ICF categories used.

(+) Covered with an ICF category either at a higher or lower level; * Category wordings of pf and nc are the codes from this study. pf, personal factor; nc, not classifiable; ODI, Oswestry Disability Index; RMDQ, Roland Morris Disability Questionnaire; NDI, Neck Disability Index; NBQ, Neck Bournemouth Questionnaire; NPDS, Neck Pain and Disability Scale.

Figures

Figure 1. Data collection and flow of analyses.

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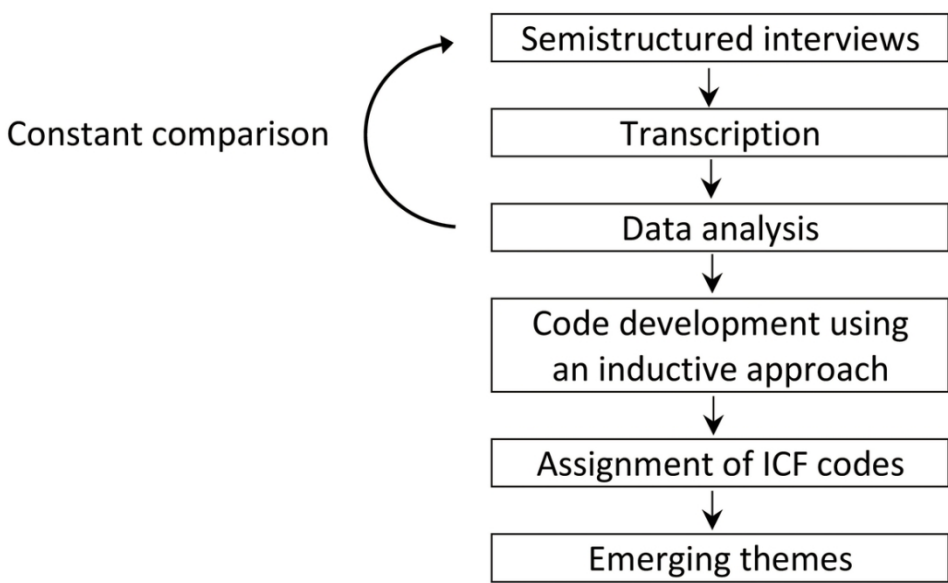


Figure 1. Data collection and flow of analyses.

103x64mm (300 x 300 DPI)

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
Title	<p>#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended</p>	1

Abstract

#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions

Introduction

#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

#4 Purpose of the study and specific objectives or questions

Methods

#5 Qualitative approach and research paradigm

Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be

discussed together.

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8	Units of study	#12	Number and relevant characteristics of participants,	9-10
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15	Data processing	#13	Methods for processing data prior to and during analysis,	7
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25	Data analysis	#14	Process by which inferences, themes, etc. were	7
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43	Results/findings			
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54	Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts,	Table 3
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56			photographs) to substantiate analytic findings	
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Discussion

Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	14-15
Limitations	#19	Trustworthiness and limitations of findings	16
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	17
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	17

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What are important consequences in children with non-specific spinal pain? A qualitative study of Danish 9-12-year olds.

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ABSTRACT

Objectives

It is currently unknown whether children, adolescents and adults experiencing non-specific spinal pain are affected by their pain in a similar manner. It is also unclear whether questionnaires developed for adults, can simply be transferred to paediatric populations. The objective of this study was to explore the physical, psychological and social consequences of a life with non-specific spinal pain among Danish children and to compare these consequences with the content of common adult questionnaires.

Design and setting

A qualitative study based on individual interviews and focus group discussions with participants recruited from two public schools in Denmark.

Participants

Thirty-six children aged 9 to 12 with spinal pain were invited to an interview using a purposive sampling strategy with age, pain intensity and frequency, and general well-being status as inclusion criteria. Nineteen (9 girls, 10 boys) accepted to participate.

Methods

Data were transcribed verbatim and coded by following a thematic approach to elicit key concepts relevant to spinal pain. Subsequently, focus group interviews were conducted, and all codes were assigned categories corresponding to the International Classification of Function, Disability and Health (ICF) for comparison to adult questionnaires.

Results

Nineteen interviews were included, and 21 individual codes identified. Across the codes, five themes emerged in relation to children's experiences of living with spinal pain: 'Sports and play', 'Axial loading', 'Coping strategies', 'Mood changes', and 'Pain anxiety'. Codes and themes were elaborated on by the focus groups. Only approximately 40% of the identified ICF categories were covered by adult spinal questionnaires.

Conclusions

The negative impact of non-specific spinal pain on 9-12-year olds pivots around codes which are considerably different to adults. Psychological and social factors were more prominent and pain anxiety was

1
2 dominant in the lived lives of children. New questionnaires should be age-specific and include the identified
3
4 codes within each theme.
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6
7

8 **Strength and limitations of this study** 9

- 10 • This is the first study using a qualitative approach to explore the consequences of non-specific spinal
11 pain in children aged 9-12
12
- 13 • Following individual interviews, results were expanded through focus group discussions
14
- 15 • Results were compared to the content of adult spinal questionnaires
16
- 17 • Findings are restricted to children aged 9 to 12 who had experienced non-trivial spinal pain
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- 19 • The results may not generalisable beyond a Scandinavian context
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INTRODUCTION

Non-specific spinal pain is common and costly among adults, and in addition to the impact on an individual level, the high prevalence of back pain is a serious socioeconomic challenge to society.^{1,2} The impact of non-specific spinal pain in children is uncertain, but according to the Global Burden of Disease Study, musculoskeletal disorders ranked tenth on the list of causes for years lived with disability among 5-14-year olds globally in 2017.³ Furthermore, but the costs of chronic pain in adolescence has been estimated to 19,5 bil. US dollars in the US, which exceeds asthma, ADHD and obesity.⁴ Prevalence rates increase with age, until reaching the same level as in adults around the age of 18.^{5,6} Furthermore, evidence suggests that back pain early in life significantly increases the risk of back pain in adulthood.⁵ Thus, childhood and early adolescence might represent critical time periods for the improvement of lifetime trajectories of back pain.

Recently, non-specific spinal pain in children and adolescents have received more attention focusing on prevalence⁷, risk factors⁸, the natural course of pain⁹ and intervention studies.¹⁰ However, our knowledge about their experiences, challenges and limitations due to back pain remains inadequate.¹¹ Most of our knowledge pertains to adults where a plethora of questionnaires have been developed and validated to assess function and limitations in back pain,¹² but no such questionnaires exist for children with non-specific spinal pain. Such questionnaires are important to measure outcomes in clinical trials as well as monitoring patient progress in clinical practice. Adults report a broad variety of consequences of non-specific back pain,^{12,13} including mental and social constraints, as well as physical limitations in everyday life, reduced working ability and various forms of mental, cognitive and social stress.¹³ The adult consequences to non-specific spinal pain are likely different in children and adolescents due to differences in cognitive and physical maturity and social status^{11,14,15}, and therefore it is unclear whether questionnaires, developed for adult populations, can simply be transferred to younger populations. Given the fact that children's cognitive levels, everyday lives and social relationships are often very different from those of adults,¹⁶ unique domains might be important for children. Furthermore, even if outcome domains for adults seem transferrable to children, it is plausible that some specific items may not be suitable in a paediatric context. Obvious examples include cleaning, work and sexual function.¹³

1
2 Current paediatric-specific pain questionnaires focus on general pain or pain related to specific diagnoses
3
4 such as cancer (Memorial Symptom Assessment Scale; a measure of symptoms in cancer)¹⁷, rheumatic
5
6 disease (The Juvenile Arthritis Multidimensional Assessment Report; a measure of well-being, pain,
7
8 functional status and quality of life)¹⁸ or abdominal pain (Children's Somatization Inventory; a measure of
9
10 bothersomeness of somatic symptoms).¹⁹ To our knowledge, only one questionnaire investigating
11
12 impairment due to paediatric back pain exists (The Paediatric Back Outcome Measure), and this is intended
13
14 for use in an a narrowly defined athletic context.²⁰ Therefore, an argument exists for the development of
15
16 questionnaires which focus on non-specific spinal pain in a general population of children. In response we
17
18 have initiated a research programme to develop a series of questionnaires measuring consequences of
19
20 musculoskeletal problems in children; the first questionnaire relating to non-specific spinal pain. Prior to the
21
22 development of a questionnaire, qualitative studies are essential for a clear conceptualization of the target
23
24 construct.²¹ This is essential to establish formal content validity, because it is during this process that the
25
26 domains (target constructs) are identified.
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29
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31
32 The present study represents the first step in the development of a paediatric questionnaire focusing on the
33
34 consequences of non-specific spinal pain. The objective is to 1) identify key domain-related concepts
35
36 relevant to non-specific spinal pain of 9-12-year-old children by exploring their own experiences of the
37
38 physical, psychological and social consequences of the pain, and 2) to compare these concepts to the content
39
40 of commonly used adult low back and neck pain questionnaires.
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43

44 **METHODS AND MATERIAL**

46 **Design**

47
48 A qualitative interview study using an inductive approach was deemed appropriate to investigate and
49
50 understand how children experience the consequences of non-specific spinal pain. This was followed by a
51
52 focus group study concentrating on elaborating and broadening the key concepts found in the interview
53
54 study. Finally, results were mapped onto the International Classification of Function, Disability and Health
55
56 (ICF) coding system to enable comparison to commonly used adult questionnaires investigating non-specific
57
58 spinal pain.
59
60

1
2 We approached this topic from a constructivist perspective, in that the researcher attempted to co-create
3
4 meaning with children with regard to the expression of their lived experiences.²²
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6
7

8 **The interview study**

9 *Semi-structured interview*

10
11 The interviews were semi-structured and followed a bio-psycho-social framework to ensure that all aspects
12
13 of the children's lives were covered. We developed an interview guide structured into two sections: 'Getting
14
15 to know the child better', and 'Talking about the back'. The first section consisted of general questions about
16
17 the child (e.g. 'Please tell me a bit about yourself?', 'What do you do in your spare time?'). The second
18
19 section comprised open questions specifically aimed at getting the child to elaborate about the back pain (e.g.
20
21 'Please tell me what you think is important about your back pain?', 'When does your back pain bother you
22
23 most?'). As the interviews were carried out with children less than or equal to 12 years of age, a member
24
25 check was not considered appropriate.
26
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28
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30

31 *Sampling strategy*

32
33 We developed a purposive sampling strategy in which we sought to interview Danish schoolchildren in the
34
35 age group 9-12 years with non-specific spinal pain.²³ The lower age limit was set to ensure the children's
36
37 cognitive and linguistic ability to understand and reflect on themselves.²⁴ The upper age limit was set to
38
39 include children before the onset of puberty, as research has shown that puberty, and especially the growth
40
41 spurt (boys around 14 years, girls about 12 years), is associated with increased incidence of spinal pain.²⁵
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45

46 Since previous studies noted discrepancies between children's and parents' reports, when it comes to the
47
48 child's experience of pain.²⁶ Therefore, it was decided not to use the parents as a proxy measure, and data
49
50 was collected directly from children to create a more reliable account of the discussed issues.¹⁶ Sample size
51
52 was not determined a priori but interviews were conducted until data saturation at each age and well-being
53
54 strata was reached.
55
56
57

58 The Young Spine Questionnaire (YSQ)²⁷ was administered to identify children suffering from non-specific
59
60 spinal pain. Since more than 80% in this group report some degree of non-specific spinal pain, most of it

1
2 trivial, inclusion was limited to children with non-trivial pain as described in Table 1.²⁸ In addition, the
3
4 children filled in the Kid-Screen 10²⁹ as a measure of mental well-being, as it is unknown whether a child's
5
6 mental well-being influences the experience of non-specific spinal pain. We categorized the children's well-
7
8 being into three groups following the instruction and the predefined groups (low, normal and high level of
9
10 well-being) from the Kid-Screen Group.²⁹
11
12
13

14 The interviewees were selected from the group of children who fulfilled the inclusion criteria listed in Table
15
16 1. All eligible children were divided into the three levels of well-being, and interviewees were randomly
17
18 drawn from the three groups to optimize equal distribution of the well-being strata. The children were able to
19
20 opt out at any time during the selection procedure and in the interview.
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25 ---- Table 1 ----
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29 *Participants*
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31 All participants were recruited from two Danish public schools in two different regions of the country.
32
33 Children with non-specific spinal pain between the ages of 9 and 12 were included.
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35
36

37 *Pilot procedures*
38

39 To ensure that all practical procedures, including the recruitment strategy, were suitable for the study, these
40
41 were tested in a pilot test conducted at a Danish public school in one region of the country and included four
42
43 children, one of each age (9-12 years) and representing both sexes as well as all three well-being groups.
44
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46
47

48 *Data collection*
49

50 Information material about the study was distributed to the teachers, children and their parents. The YSQ²⁷
51
52 and the Kid-Screen 10²⁹ questionnaires were handed out to all pupils in the 3rd to 6th grade, covering the
53
54 appropriate age range, at the two participating schools. Parents to the children selected for interviews
55
56 received additional information about the objectives and procedures for the interview and returned informed
57
58 consent. Before conducting each interview, the answers on the YSQ were examined by the interviewer.
59
60

1
2 One of the authors (ABS) conducted all interviews from January 2017 to March 2017 within a week after the
3
4 child had completed the questionnaires. The face-to-face approach was chosen to allow co-creation of
5
6 meaning by reconstructing perceptions of experiences and events related to non-specific spinal pain.³⁰ A full
7
8 body drawing, and the revised faces pain scale (FPS-R)³¹ were initially used to ensure that the painful area
9
10 pertained to the spine and the intensity of the pain.³² Otherwise the children were free to express themselves
11
12 freely during the interview.
13

14
15
16 A maximum of two interviews were carried out per day, and all interviews were recorded and transcribed for
17
18 analysis prior to conducting further interviews. The interviews were carried out at the participants' schools
19
20 during normal school hours. Participants were told that they were free to terminate the interview at any time.
21
22

23 24 25 *Data analysis*

26
27 The transcription was performed by ABS and coding was carried out inductively by two authors (ABS and
28
29 CM) to facilitate the emergence of general themes of key concepts relevant to non-specific spinal pain. A
30
31 thematic approach using five steps (data familiarisation, generating initial codes, searching for themes,
32
33 reviewing themes and defining and naming themes) as outlined by Braun & Clarke was used.³³ Themes
34
35 relating to children's experience of non-specific spinal pain and the consequences thereof were then
36
37 identified among all the authors across the codes. The process of the data collection and analysis is shown in
38
39 Figure 1.
40

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43
44 ---- **Figure 1** ----
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46
47
48 Coding and analysis were carried out using the Atlas Ti computer assisted qualitative data analysis software
49
50 package version 1.0.49, and data were treated confidentially and anonymized in connection with the
51
52 transcription.
53

54 55 56 **Focus group study**

57
58 A further focused exploration and elaboration of the codes and key concepts identified in the interview study
59
60 was performed in a focus group study.³⁴ The express purpose was to ensure that respondents consistently

1
2 include and exclude the same features of the construct. This process required significantly more prompting
3
4 from the investigators and was therefore best accomplished through focus group interviews. These were
5
6 conducted by three of the authors (ABS, HHL and LH) on the largest of the two schools.
7
8
9

10 *Participants*

11
12 Based on the questionnaires from the first part of the study, four children, who had not been interviewed
13
14 previously, were selected from each grade (3rd-6th) based on the criteria in Table 1. The participants were
15
16 divided into two focus groups comprising eight children in each group. New information material and
17
18 parental consent forms were distributed, inviting the children to a focus group discussion at the school.
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23 *Materials*

24
25 We developed multiple sets of cards with one code written on each card. Each set of cards included all the
26
27 identified codes from the interview study. An A3 poster was developed for each theme including relevant
28
29 theme words (identified in the interview study) and one or two visual drawings. The drawings for each theme
30
31 were developed by the author group. Sticky tacks were provided to the children during the phase of placing
32
33 the cards on the theme posters.
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38 *Exploration and elaboration of the codes and themes*

39
40 Children with signed informed consent were gathered for a three-hour session at the school. First, the
41
42 children in each focus group received a set of cards with all the codes. They were asked to sort the cards into
43
44 two piles: one with relevant (i.e. this applied to me, when I had the pain) and one with irrelevant (i.e. this did
45
46 not apply to me, when I had the pain) in relation to their experience of non-specific spinal pain. This was
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48 done individually followed by a break, allowing the researchers to note the results. Following this, all the
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50 codes were discussed first within the two focus groups and subsequently in a plenum discussion involving all
51
52 the children, with the researchers initiating the discussion being aware of elaborations of existing codes and
53
54 the emergence of new ones. Next, the themes which emerged through the analysis of the interview study
55
56 were presented and explained to the children, followed by examples of possible theme-categorizations of
57
58 each code. Finally, the A3 posters reflecting each theme were placed on the wall, and the children placed
59
60 their cards with relevant codes on the poster they considered to be best fitting.

Code mapping to the ICF and comparison to adult questionnaires

All the identified codes were assigned corresponding categories using the ICF for comparison with commonly used questionnaires designed for adults. The ICF framework was chosen because it allows direct comparison between questionnaires by assigning codes from the framework to individual items, indicating similarity of content³⁵. Two researchers (LH and HHL) assigned ICF categories independently to each code using the linking rules defined by Cieza et al.^{36 37} The assigned ICF categories from the two researchers were compared. If minor classification disagreements occurred (at the second or third level), a consensus-based process was implemented. In case major disagreement (at the component or chapter level), an external expert who has previously used the ICF extensively was consulted.

Our ICF categories were compared to the content of questionnaires commonly used to assess the consequences of low back pain (LBP) and neck pain (NP) in adults to elucidate whether the content of adult questionnaires would cover what children consider relevant.

We chose to compare our codes to the two most commonly used low back specific questionnaires: the Oswestry Disability Index, and the 24-item Roland-Morris Disability Questionnaire,³⁸ and three commonly used neck specific questionnaires: The Neck Disability Index, the Neck Bournemouth Questionnaire, and the Neck Pain and Disability Scale.³⁹ ICF categories for each questionnaire were derived from published literature.³⁹⁻⁴²

Patient and public involvement

The public was not involved in the design, conduct, reporting, or dissemination of this study.

Ethical approval

The study was approved by the Danish Data Protection Agency (J.nr. 2015-57-0008) but approval was not required from the local ethics committee according to Danish law.⁴³

1
2 A reporting checklist for qualitative studies was used to ensure adherence to the key elements when reporting
3 qualitative studies.⁴⁴
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8 **RESULTS**

9 **The interview study**

10 *Pilot procedure*

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12 The practical procedures involved in recruiting the children, receiving informed consent and setting up an
13 interview were tested on four children in one public school. This resulted in minor adjustments to the
14 procedures of recruiting the children and who to communicate with at the school. Data from the pilot
15 procedure were not included in main analyses.
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25 *Participants*

26
27 In the two schools combined, 338 children completed the YSQ and the Kid-Screen 10, and 199 of these
28 fulfilled all inclusion criteria (41%). After stratification according to age and mental well-being, 36 children
29 were invited for interviews and a total of 20 children accepted and were interviewed (one interview was
30 excluded due to the exclusion criterion 'musculoskeletal diagnosis'). Nine girls and ten boys from 9-12 years
31 spread across the three well-being strata were included. The characteristics of the interviewees are shown in
32 Table 2.
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44 **---- Table 2 ----**

45 *Data collection and saturation*

46
47 The interviews lasted from 15 to 30 minutes, and no participants chose to terminate the interview. Data
48 saturation was achieved at interview number 16. To investigate a potential geographic variation, interviews
49 17-19 were conducted at a school in another region of Denmark, but no new aspects came up. No noteworthy
50 differences were found between ages, gender, geographic location or well-being levels.
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56 *Codes and emerging themes*

57
58 A total of 21 individual codes were created and examples of key quotes for each code can be seen Table 3.
59
60 The references are shown as '#Y:Z' where Y refers to the individual and Z to the quote number.

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4 ---- Table 3 ----
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8 Across the 21 codes, five themes emerged in relation to the children's experiences of living with non-
9 specific spinal pain. The five themes were: 'Sports and play', 'Axial loading', 'Coping strategies', 'Mood
10 changes' and 'Pain anxiety'. Table 4 provides an overview of the thematic analysis, and the codes
11 represented in the five themes.
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18 ---- Table 4 ----
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22 Each of the five themes are presented and described in detail below with examples of quotes noted in
23 parentheses.
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29 *(a) Sports and play*
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31 Physical limitations, such as staying away from sports or not being able to play with friends were one of the
32 main complaints for the children (#17:2). In general, the children reported frustration and concern when they
33 were unable to participate in sports and activities at the same level as their friends (#8:5). Some of the
34 children tried to find a way to participate, either by communicating their pain (#3:47), or by finding another
35 role in the game which was less physically demanding (#10:6). Some children would isolate themselves or
36 find alternative solutions, e.g. by playing with another group of children engaging in less physically
37 demanding games or sports (#5:73).
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48 *(b) Axial loading*
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50 Axial loading was reported to be a risk factor for developing as well as maintaining spinal pain. Jumping on
51 a trampoline was stated as a triggering cause of pain by a significant number of the interviewees (#7:13).
52 Many reported that they felt unable to jump on the trampoline as it increased their spinal pain (#7:8).
53 Walking with a heavy school bag (#4:15), playing computer games (#5:50), or sitting down in school (#9:2)
54 were reported as other causes for an increase in spinal pain. It was also reported that the ability to
55 concentrate was affected by spinal pain, when sitting down for longer periods e.g. in school (#9:2).
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4 *(c) Coping strategies*
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6 Many children tried to find a logical explanation for the cause of their pain experience (#13:16) to
7 understand or cope with their limitations and frustrations. A group of children reported that they didn't know
8 how to get pain relief (#18:6). This contrasted with a larger group of the children, who tried to help
9 themselves either actively or passively. Examples of active distraction strategies were playing with friends
10 (#5:44), doing sports (#2:22), going to school (#19:22), exercises (#12:18) or stretching the back (#15:18).
11 Examples of passive strategies to reduce spinal pain could be lying down (#13:27), restricting movements or
12 avoiding specific movements (#5:54), indicating a certain movement anxiety. A group of children even
13 reported that they were extremely aware of what they carried on their backs, e.g. heavy school bags (#2:107)
14 (this was also noted in the axial loading theme, above).
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27 A cognitive approach was reported by some children whereby they tried to focus on something else to make
28 the pain disappear (#11:30). A couple of the children even said that they would hurt themselves e.g. by
29 pressing a hand to the back to reduce the spinal pain (#2:87). In general, the children reported less pain when
30 they were distracted by physical, psychological or social inputs.
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38 Some of the children were afraid of being misunderstood and therefore talked about their spinal pain
39 primarily with people who had themselves suffered from spinal pain (#10:3). The children most frequently
40 reported that they talk primarily with their parents (#19:14), and secondarily with friends (#10:3) or sports
41 coaches (#17:14) about their spinal pain.
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48 *(d) Mood changes*
49

50 Nearly all children indicated frustration and incomprehension about their spinal pain (#5:61). A large group
51 of children expressed a relation between their mood and the spinal pain, especially feeling sad and frustrated
52 due to pain (#3:48). Some children also implied that their negative mood was caused by lack of sleep, and
53 that reduced sleep was due to excessive back pain (#3:48). A few reported difficulties concentrating when
54 experiencing spinal pain (#19:12). Although a good mood could reduce the pain, the children often
55 continued to feel the pain, and some were even afraid to show it in class or to teammates (#2:79).
56
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(e) Pain anxiety

A group of children reported no problems related to their spinal pain. There was some indication that they coped with the pain as if it was a cold or stomachache, which would go away by itself (#15:23). However, another group of children articulated some level of concern when experiencing spinal pain. There was a large variation in how often, how much and which aspects concerned the children. Some worried that they could not keep up with school work and that absence would influence their future lives (#10:30), while others feared they would get the same physical limitation as they knew from their parents (#5:62). Some children were extremely worried and reported that they could hardly cope due to the pain intensity combined with their thoughts and concerns about the pain (#7:20). The children who were concerned indicated that they were more careful regarding their backs, even when not experiencing spinal pain (#19:19). Some of the children were even afraid to become isolated from their friends if they told them about the pain (#2:97).

Group differences

A comparison of the emerging themes across age groups, gender and well-being did not reveal any differences among the groups.

Salient issues

Two issues were not included as codes in Table 3, since they did not describe consequences of pain. 'No limitations' represented children that were not affected or limited by spinal pain in everyday life despite fulfilling the inclusion criteria for spinal pain, and 'Cause not known' was important to some children but has not been explored further in this study because it refers to aetiology.

The analysis also identified four codes which described the area of consequences with the most impact on the child (i.e. movement, pain, psychological factors and social limitations). Each code commenced with 'Worst is...' and arose from specific questioning and were therefore not assigned to a specific theme.

The focus group study

1
2 Sixteen children participated in the focus group with all four grades represented (3rd – 6th). All the
3
4 previously identified codes were chosen by at least two children as being relevant, with nine of the 21 codes
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6 being chosen by five or more participants. It was possible to include all children in the follow-up discussion,
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8 but despite a long and lively discussion, no new codes emerged. There was a large uncertainty among the
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10 children about categorizing the codes into themes, reflecting the complexity of the task and that some codes
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12 are represented in more than one theme.
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16 **Code mapping to the ICF and comparison to adult questionnaires**

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18 Of the 21 identified codes, five were classified into the ‘Body functions’ component (one shared with the
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20 ‘Personal factors’ component), eight into the ‘Activities and participation’ component (one shared with the
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22 ‘Body structures’ component), one as an ‘Environmental factor’, and four as ‘Personal factors’. Five codes
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24 were not classifiable, whereof four related to the specific question: ‘What is worst?’ (codes 18-21). Some
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26 codes could be assigned more than one ICF category, and therefore the final number of ICF categories was
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28 24. According to the categorization rules by Cieza et al., ICF category b280 (sensation of pain) should have
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30 been used for several of the codes. However, ‘sensation of pain’ is indirectly related to all the codes, since
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32 they refer to non-specific spinal pain, and therefore we chose only to use b280 for ‘pain intensity’, which is a
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34 direct expression of the pain sensation.^{36 37} The ICF categories have been added to Table 3.
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40 The items in the adult questionnaires were categorized within the ICF components of ‘Body functions’, and
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42 ‘Activities and participation’, whereas ‘Personal factors’, which the children found very important, were not
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44 covered (Table 5). A total of 10 out of 24 ICF categories (42%) were covered by at least one adult LBP
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46 questionnaire whereas nine (38%) were covered by adult NP questionnaires. Three categories in ‘Body
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48 functions’ (sleep, emotional function, and sensation of pain) and two in ‘Activities and participation’ (lifting
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50 and carrying, and sports) were included in most questionnaires whereas 11 ICF categories were not included
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52 in any of the five adult questionnaires (one in ‘Body functions’, five in ‘Activities and participation’, one in
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54 ‘Environmental factors’, three ‘Personal factors’ and one ‘not classifiable’).
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58 The content of the children’s codes and the content of the adult questionnaire items within each ICF category
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60 differed considerably at times. For example, the ICF category of ‘Play’ (d9200) related to a physical

1 limitation in the children (e.g. staying at home, not being able to do the same activities as one's peers)
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4 whereas it related to restrictions in recreational activities (i.e. 'Reading', item 4 in the Neck Disability Index;
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6 'Family activities', item 3 in the Neck Bournemouth Questionnaire; 'Interference with social activities', item
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8 8 in the Neck Pain and Disability Scale) in the adult questionnaire items.
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16 **DISCUSSION**

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18 Precise conceptualization of a target construct is critical to the validity cascade, but also ultimately the
19 application of a questionnaire.⁴⁵ Therefore, the key contribution of this investigation lies arguably in the
20 identification of the consequences of living with non-specific spinal pain in a population of 9-12-years old
21 children. It has previously been reasoned and observed that a poorly conceptualized target construct will
22 inevitably result in measurement error.^{21 34} As such, it was the express objective in this investigation to elicit
23 detailed descriptions of non-specific spinal pain experiences from a group of 9-12-year old children
24 resembling the population a future instrument will be applied to. Thus, the focus of this study is the
25 development of a new questionnaire, but nevertheless results can be used broadly to inform researchers and
26 clinicians working with children with non-specific spinal pain.
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40 The interviews revealed 21 codes, of which 17 could be classified into five themes: 'Sports and play', 'Axial
41 loading', 'Coping strategies', 'Mood changes' and 'Pain anxiety'. Several codes were represented in more
42 than one theme, and we observed the physical experience in the 'sport and play' theme as the dominant
43 cognitive hub through which this group of children access and link the psychological and social domains.
44 We also observed that the anxiety at times could appear counterproductive and possibly add to a negative
45 trajectory of pain. We therefore recommend that this is addressed explicitly in future programmes for
46 treatment and prevention of non-specific spinal pain in children.
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56 Two issues were not included in the identified codes, although appearing several times. The first was 'no
57 limitation', demonstrating the important fact that some children do not experience any limitations at all,
58 despite fulfilling the inclusion criteria of non-specific spinal pain 'sometimes or often' and three or more on
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1
2 the FPS-R. This could indicate that some children are capable of handling pain of moderate intensity and
3
4 frequency without it causing any physical or psychosocial limitations. Another reason could relate to
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6 uncertainty regarding the validity of self-reported pain in children⁴⁶. The other issue was ‘cause not known’
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8 reflecting the children’s desire to know why they had pain. This was excluded as it refers to aetiology of the
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10 pain. It did, however, reflect a strong desire among the children to understand their pain, although the
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12 interviewer attempted to focus on the consequences of it. This desire was also obvious during group
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14 discussions and may partly explain the prominent pain anxiety experienced by the children.
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19 The study also revealed four areas of impact as a result of the non-specific spinal pain. These arose from
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21 direct questioning (‘What is worst?’) and were limitations in movement, pain, psychological factors and
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23 social limitations. Distinction between these areas are important from a clinical point of view as enquiring
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25 about them have the potential for the clinician to direct treatment, or anxiety-reducing advice and support, to
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27 a specific domain.
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32 When comparing the identified codes to the content in adult questionnaires, only approximately 40% of the
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34 ICF categories were covered and this related mainly to the component of ‘physical functioning’ which is
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36 recommended as a core outcome for adults with low back pain.¹³ Psychological and social factors were much
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38 more prominent to the lived life of children and pain anxiety was a dominant theme with many children
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40 expressing fear of future pain. Therefore, it appears clear, that questionnaires developed for adults are not
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42 adequate for paediatric populations.
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45 46 **Strength and limitations**

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48 This is the first study using a formal qualitative approach to explore the consequences of non-specific spinal
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50 pain in children aged 9-12. We believe our study findings are transferrable to settings with a similar school
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52 structure and sociodemographic composition, typically the Scandinavian countries. However, the results may
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54 not be generalisable beyond the Scandinavian culture as pain narratives may be influenced by socio-cultural
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56 factors.⁴⁷ Therefore, we recommend that studies exploring pain narratives in this age group are carried out in
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58 other cultures and the results compared to ours.
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2 In addition, the findings are only applicable to children in a narrow age range from 9 to 12 years. We advise
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4 caution using the results in younger or older children as the experienced consequences of non-specific spinal
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6 pain may differ substantially. Further studies in adolescents are warranted.
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10 **CONCLUSION**

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12 For some children, non-specific spinal pain sets off a cascade of negative consequences, that affects their
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14 everyday life in five key domains. 'Sport and play' and 'axial loading' correspond particularly well with the
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16 'physical function' domain recommended for the adult populations. Interestingly though, although the
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18 overall categories identified were similar to those found in adult populations, individual codes for the
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20 children differ significantly from their adult counterparts. Our results confirmed that the perceptions of the
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22 consequences of non-specific spinal pain in children aged 9-12 years is complex, but also that some children
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24 do *not* experience any consequences despite reporting non-trivial spinal pain. We recommend the identified
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26 themes and codes serve as a starting point for the development of a new questionnaire.
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Competing interests

The authors declare that they have no competing interests.

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Author contributions

HHL and LH conceived the study and AS, HHL, CM and LH participated in the design and coordination of it. AS carried out the interviews and the coding of the material, and HHL, AS and LH carried out the confirmatory study. HHL and LH performed the coding and comparison to the adult questionnaires. HHL, AS, CM and LH drafted the manuscript and all authors read and approved the final manuscript.

Availability of data and materials

Data are not available due to legal (GDPR) and ethical restrictions.

Tables

Table 1. Inclusion and exclusion criteria.

Inclusion criteria
<ul style="list-style-type: none"> • Children 9-12 years of age with non-specific pain in one or more parts of the spine • A pain intensity of at least face number three on the revised Faces Pain scale in the YSQ* • Children indicating having non-specific spinal pain 'sometimes' or 'often' in the YSQ • Written permission to participate in the project from a parent/guardian
Exclusion criteria
<ul style="list-style-type: none"> • Children who do not understand or speak Danish • Children with diagnosed musculoskeletal disorders (e.g. Muscular Dystrophy, Juvenile Osteoporosis, Congenital Myopathy)

* YSQ, Young Spine Questionnaire

Table 2. The distribution of all participants according to age, gender and well-being.

	Well-being	9 years	10 years	11 years	12 years	13 years	Total
Girls spinal pain \geq 3 FPS-R	Low	6 (0)	10 (0)	6 (0)	2 (1)	0 (0)	24 (1)
	Normal	14 (1)	23 (1)	18 (2)	16 (2)	9 (0)	80 (6)
	High	2 (0)	1 (1)	0 (0)	3 (1)	0 (0)	6 (2)
Boys spinal pain \geq 3 FPS-R	Low	3 (1)	5 (0)	3 (1)	1 (0)	0 (0)	12 (2)
	Normal	10 (0)	15 (2)	17 (4)	12 (2)	8 (0)	62 (8)
	High	0 (0)	1 (0)	1 (0)	13 (1)	0 (0)	15 (1)
Total spinal pain \geq 3 FPS-R		35 (2)	55 (4)	45 (7)	47 (7)	17 (0)	199 (20)

Note: Shows the distribution of eligible participants with non-specific spinal pain equal to or more than 2 on the FPS-R, who also reported spinal pain 'sometimes' or 'often' stratified according to their well-being. The number in () is the number of participating interviewees.

FPS-R, revised Faces Pain Scale

Table 3. Codes, key quotations and corresponding ICF categories

Codes	Key quotations	Reference	ICF category
Body functions			
1. Affected sleep	'I remember having difficulties falling asleep, as I could not lie down properly. I had to fall asleep as fast as possible, in order not to feel the pain when I turned, as that woke me up, (I: Have you tried waking up due to pain?) Yes.'	#19:4	b134
2. Worrying about spinal pain	'Well, I'm afraid I can't do the same things as other children, and then I can't play with them. It is also really difficult to bicycle home and everything ...'	#1:55	b152
3. Pain intensity	'...It just stops like, I almost can't breathe ...'	#5:55	b280
4. Difficulties to define the pain*	'... One night, I was just about to go to bed, my mom asked if I was feeling alright, I told her that my back really hurt. She then said I should see a chiropractor. ... It was hard to find out where it hurt so much, which was really annoying as I could not tell my mom, or the chiropractor.'	#19:7	b280 b780 pf
Activities and participation			

5. Talking with parents	‘Yes, I talked with them as I had to, and you should know that you need to be talked with...because it helps. It helped me a lot to talk with my parents about the pain’	#19:14	d350 d7601
6. Talking with friends	‘Sometimes, I tell that I have pain in my back, so I can’t play too wildly ...’	#7:23	d350 d7500 d7504
7. Do not want to talk with others about the pain	‘... I have not talked with them ... I just wanted to keep it to myself as I thought it could be really uncomfortable if other people knew that I have back pain. ... It is just something one have, and they don’t like to let other people know ...’	#19:15	d350 d710
8. Maintaining static postures	‘... You sit down for many hours and when standing up or move a bit, it starts hurting really really bad ...’	#10:17	d4150 d4153 d4154 d4155
9. Spinal load	‘.. it also hurts when I carry my bag, and the pain increases... (I: Is there a difference in carrying light and heavy stuff?) Yes, often if I have to carry a heavy bag, which gives me a headache ‘	#7:2	d430
10. Social limitation	‘Sometimes when I am asked if I can play, I say no, I just want to go home and rest. I don’t say that I have back pain, I just say I think that I want to go home and rest.’	#5:66	d750
11. Physical limitation**	‘... I can’t do the same activities, e.g. running, as the boys,...’	#3:44	d9200 d9201 d9205 b7
12. Reduction in participation	‘... I have had to stay home because I almost couldn’t stand up ...’	#10:12	d9200 d9201 d9205
Environmental factors			
13. Treatment tried/not tried	‘Yes, a lot. Often I go to my mom’s chiropractor, as he puts anything in place, and stuff like that.’ ‘No, not really. My mom tried to give me massage when I came home from handball as she knows where it hurts, because she is a nurse and have worked at a hospital.’	#9:8 #10:15	e580
Personal factors			
14. Improving factors	‘We have put less in my bag, so I only have to carry the most necessary stuff, and not even a pencil more (I: Can you feel that it helps?) Yes, it helps me, because the bag is less heavy than before, and I have less pain...’	#2:107	pf
15. Worsening factors	‘... I will not run as much as I normally do. (I: Why not?) as I can feel that it starts to hurt more.’	#14:1	pf
16. Strategies to avoid pain	‘When I sit down, then I first have to sit on my hands, as this somehow reduces the pain. I will then let go, which soothes the pain somewhat.’	#10:20	pf

Not classifiable			
17. Cause of pain known/unknown	‘It will hurt in my back, if I jump too much on the trampoline.’	#7:8	nc
	‘I actually don’t think I know why I had pain. Maybe it was because I had just made a wrong movement, or something with my neck while sleeping or something. I don’t really know.’	#17:4	
18. Worst is movement	‘The very worst, I think the worst, is to jump rope ... because I have to jump up and down, up and down.’	#3:54	nc
19. Worst is pain	‘It just hurts really bad - I can’t even go to the toilet, even though I have to (I: Is that because it hurts to walking to the toilet?) [Participant nodding].’	#1:17	nc
20. Worst is psychological factors	‘I think it is the feeling you have in the back, as it can make a bad day worse.’	#15:21	nc
21. Worst is social limitation	‘It must be that I am unable to do the same as all of my friends – that must be the worst as I feel a bit left out.’	#10:16	nc

Note: pf, personal factor; nc, not classifiable

* The code ‘Difficulties to define the pain’ appears once but has been classified as both ‘Body functions’ and ‘Personal factors’.

** The code ‘Physical limitation’ appears once but has been classified under ‘Activities and participation’ and ‘Body functions’.

Table 4. Thematic analysis.

Themes	Codes
‘Sports and play’	Pain intensity (b) Worrying about spinal pain (b) Physical limitation (d, s) Reduction in participation (d) Talking with friends (d) Social limitation (d) Strategies to avoid pain (pf)
‘Axial loading’	Pain intensity (b) Spinal load (d) Maintaining static postures (d) Social limitation (d) Cause of pain known/unknown (nc) Worsening factors (nc)
‘Coping strategies’	Difficulties to define the pain (b) Worrying about spinal pain (b) Physical limitation (d, s) Talking with parents (d) Talking with friends (d) Do not want to talk with others about the pain (d) Spinal load (d) Social limitation (d) Reduction in participation (d) Improving factors (pf) Strategies to avoid pain (pf) Treatment tried/not tried (e)

	Cause of pain known/unknown (nc) Worsening factors (pf)
'Mood changes'	Affected sleep (b) Worrying about spinal pain (b) Talking with parents (d) Social limitation (d) Improving factors (pf)
'Pain anxiety'	Worrying about spinal pain (b) Physical limitation (d, s)

Note: The four codes 'Worst is...' are not included in the themes as they arose from a specific question. Some of the codes appears in several of the themes. The main ICF component are in (): b, 'Body function'; d, 'Activities and participation'; e, 'Environmental factors'; s, 'Body structure'; pf, 'Personal factors'; nc, 'Not classifiable'.

Table 5. Comparison of ICF categories found in children aged 9-12 to what is covered in commonly used adult low back and neck pain questionnaires.

Category	ICF Description	Low back pain questionnaires		Neck pain questionnaires		
		ODI ^{40 41}	RMDQ ⁴⁰	NDI ^{39 42}	NBQ ^{39 42}	NPDS ^{39 42}
Body functions						
b134	Sleep function	+	+	+		+
b152	Emotional function	+	+		+	+
b280	Sensation of pain	+	+	+	+	+
b7	Neuromusculoskeletal and movement-related functions					(+)
b780	Sensations related to muscles and movement functions					
Activities and participation						
d350	Conversation					
d430	Lifting and carrying objects	+	+	+	+	
d710	Basic interpersonal interactions					
d750	Informal social relationships	+				+
d4150	Maintaining a lying position	+				
d4153	Maintaining a sitting position	+	+			
d4154	Maintaining a standing position	+	+			
d4155	Maintaining head position					
d7500	Informal relationships with friends					
d7504	Informal relationships with peers					
d7601	Child-parent relationships					
d9200	Play			(+)	(+)	(+)
d9201	Sports			(+)	(+)	(+)
d9205	Socialising	+			(+)	+
Environmental factors						
e580	Health services, systems and policies					
Other*						
pf	Improving factors					
pf	Worsening factors					
pf	Strategies to avoid pain					
nc	Cause of pain known/unknown					

Note: As Wang (2012) and Wiitavaara (2018) both include the ODI, the ICF classifications have been combined to include all ICF categories used.

(+) Covered with an ICF category either at a higher or lower level; * Category wordings of pf and nc are the codes from this study. pf, personal factor; nc, not classifiable; ODI, Oswestry Disability Index; RMDQ, Roland Morris Disability Questionnaire; NDI, Neck Disability Index; NBQ, Neck Bournemouth Questionnaire; NPDS, Neck Pain and Disability Scale.

Figures

Figure 1. Data collection and flow of analyses.

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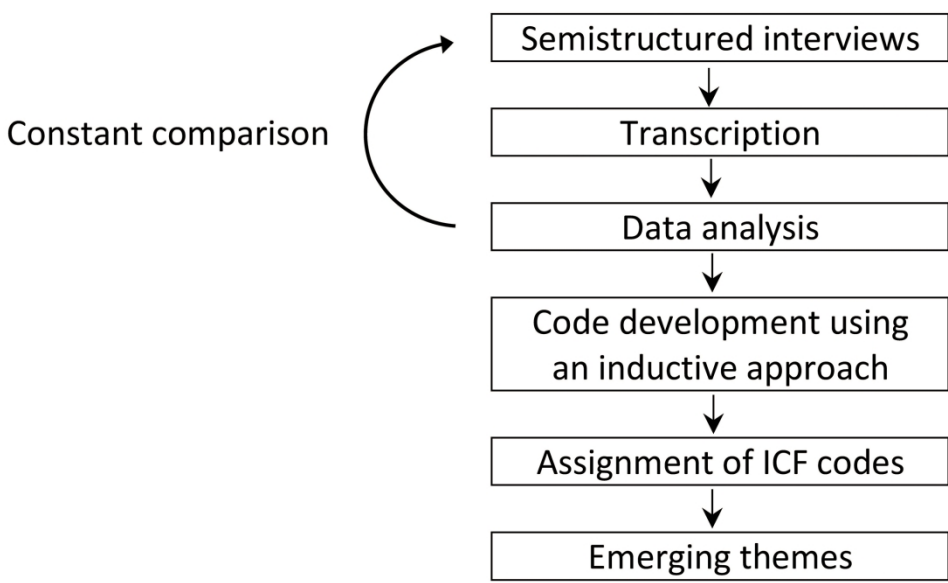


Figure 1. Data collection and flow of analyses.

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What are important consequences in children with non-specific spinal pain? A qualitative study of Danish 9-12-year olds

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What are important consequences in children with non-specific spinal pain? A qualitative study of Danish 9-12-year olds.

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ABSTRACT

Objectives

It is currently unknown whether children, adolescents and adults experiencing non-specific spinal pain are affected by their pain in a similar manner. It is also unclear whether questionnaires developed for adults, can simply be transferred to paediatric populations. The objective of this study was to explore the physical, psychological and social consequences of a life with non-specific spinal pain among Danish children and to compare these consequences with the content of common adult questionnaires.

Design and setting

A qualitative study based on individual interviews and focus group discussions with participants recruited from two public schools in Denmark.

Participants

Thirty-six children aged 9 to 12 with spinal pain were invited to an interview using a purposive sampling strategy with age, pain intensity and frequency, and general well-being status as inclusion criteria. Nineteen (9 girls, 10 boys) accepted to participate.

Methods

Data were transcribed verbatim and coded by following a thematic approach to elicit key concepts relevant to spinal pain. Subsequently, focus group interviews were conducted, and all codes were assigned categories corresponding to the International Classification of Function, Disability and Health (ICF) for comparison to adult questionnaires.

Results

Nineteen interviews were included, and 21 individual codes identified. Across the codes, five themes emerged in relation to children's experiences of living with spinal pain: 'Sports and play', 'Axial loading', 'Coping strategies', 'Mood changes', and 'Pain anxiety'. Codes and themes were elaborated on by the focus groups. Only approximately 40% of the identified ICF categories were covered by adult spinal questionnaires.

Conclusions

The negative impact of non-specific spinal pain on 9-12-year olds pivots around codes which are considerably different to adults. Psychological and social factors were more prominent and pain anxiety was

1
2 dominant in the lived lives of children. New questionnaires should be age-specific and include the identified
3
4 codes within each theme.
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7

8 **Strength and limitations of this study** 9

- 10 • This is the first study using a qualitative approach to explore the consequences of non-specific spinal
11 pain in children aged 9-12
12
- 13 • Following individual interviews, results were expanded through focus group discussions
14
- 15 • Results were compared to the content of adult spinal questionnaires
16
- 17 • Findings are restricted to children aged 9 to 12 who had experienced non-trivial spinal pain
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- 19 • The results may not generalisable beyond a Scandinavian context
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INTRODUCTION

Non-specific spinal pain is common and costly among adults, and in addition to the impact on an individual level, the high prevalence of back pain is a serious socioeconomic challenge to society.^{1,2} The impact of non-specific spinal pain in children is uncertain, but according to the Global Burden of Disease Study, musculoskeletal disorders ranked tenth on the list of causes for years lived with disability among 5-14-year olds globally in 2017.³ Furthermore, but the costs of chronic pain in adolescence has been estimated to 19,5 bil. US dollars in the US, which exceeds asthma, ADHD and obesity.⁴ Prevalence rates increase with age, until reaching the same level as in adults around the age of 18.^{5,6} Furthermore, evidence suggests that back pain early in life significantly increases the risk of back pain in adulthood.⁵ Thus, childhood and early adolescence might represent critical time periods for the improvement of lifetime trajectories of back pain.

Recently, non-specific spinal pain in children and adolescents have received more attention focusing on prevalence⁷, risk factors⁸, the natural course of pain⁹ and intervention studies.¹⁰ However, our knowledge about their experiences, challenges and limitations due to back pain remains inadequate.¹¹ Most of our knowledge pertains to adults where a plethora of questionnaires have been developed and validated to assess function and limitations in back pain,¹² but no such questionnaires exist for children with non-specific spinal pain. Such questionnaires are important to measure outcomes in clinical trials as well as monitoring patient progress in clinical practice. Adults report a broad variety of consequences of non-specific back pain,^{12,13} including mental and social constraints, as well as physical limitations in everyday life, reduced working ability and various forms of mental, cognitive and social stress.¹³ The adult consequences to non-specific spinal pain are likely different in children and adolescents due to differences in cognitive and physical maturity and social status^{11,14,15}, and therefore it is unclear whether questionnaires, developed for adult populations, can simply be transferred to younger populations. Given the fact that children's cognitive levels, everyday lives and social relationships are often very different from those of adults,¹⁶ unique domains might be important for children. Furthermore, even if outcome domains for adults seem transferrable to children, it is plausible that some specific items may not be suitable in a paediatric context. Obvious examples include cleaning, work and sexual function.¹³

1
2 Current paediatric-specific pain questionnaires focus on general pain or pain related to specific diagnoses
3
4 such as cancer (Memorial Symptom Assessment Scale; a measure of symptoms in cancer)¹⁷, rheumatic
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6 disease (The Juvenile Arthritis Multidimensional Assessment Report; a measure of well-being, pain,
7
8 functional status and quality of life)¹⁸ or abdominal pain (Children's Somatization Inventory; a measure of
9
10 bothersomeness of somatic symptoms).¹⁹ To our knowledge, only one questionnaire investigating
11
12 impairment due to paediatric back pain exists (The Paediatric Back Outcome Measure), and this is intended
13
14 for use in an a narrowly defined athletic context.²⁰ Therefore, an argument exists for the development of
15
16 questionnaires which focus on non-specific spinal pain in a general population of children. In response we
17
18 have initiated a research programme to develop a series of questionnaires measuring consequences of
19
20 musculoskeletal problems in children; the first questionnaire relating to non-specific spinal pain. Prior to the
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22 development of a questionnaire, qualitative studies are essential for a clear conceptualization of the target
23
24 construct.²¹ This is essential to establish formal content validity, because it is during this process that the
25
26 domains (target constructs) are identified.
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32 The present study represents the first step in the development of a paediatric questionnaire focusing on the
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34 consequences of non-specific spinal pain. The objective is to 1) identify key domain-related concepts
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36 relevant to non-specific spinal pain of 9-12-year-old children by exploring their own experiences of the
37
38 physical, psychological and social consequences of the pain, and 2) to compare these concepts to the content
39
40 of commonly used adult low back and neck pain questionnaires.
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44 **METHODS AND MATERIAL**

46 **Design**

47
48 A qualitative interview study using an inductive approach was deemed appropriate to investigate and
49
50 understand how children experience the consequences of non-specific spinal pain. This was followed by a
51
52 focus group study concentrating on elaborating and broadening the key concepts found in the interview
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54 study. Finally, results were mapped onto the International Classification of Function, Disability and Health
55
56 (ICF) coding system to enable comparison to commonly used adult questionnaires investigating non-specific
57
58 spinal pain.
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2 We approached this topic from a constructivist perspective, in that the researcher attempted to co-create
3
4 meaning with children with regard to the expression of their lived experiences.²²
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8 **The interview study**

9 *Semi-structured interview*

10
11 The interviews were semi-structured and followed a bio-psycho-social framework to ensure that all aspects
12
13 of the children's lives were covered. We developed an interview guide structured into two sections: 'Getting
14
15 to know the child better', and 'Talking about the back'. The first section consisted of general questions about
16
17 the child (e.g. 'Please tell me a bit about yourself?', 'What do you do in your spare time?'). The second
18
19 section comprised open questions specifically aimed at getting the child to elaborate about the back pain (e.g.
20
21 'Please tell me what you think is important about your back pain?', 'When does your back pain bother you
22
23 most?'). As the interviews were carried out with children less than or equal to 12 years of age, a member
24
25 check was not considered appropriate.
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31 *Sampling strategy*

32
33 We developed a purposive sampling strategy in which we sought to interview Danish schoolchildren in the
34
35 age group 9-12 years with non-specific spinal pain.²³ The lower age limit was set to ensure the children's
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37 cognitive and linguistic ability to understand and reflect on themselves.²⁴ The upper age limit was set to
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39 include children before the onset of puberty, as research has shown that puberty, and especially the growth
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41 spurt (boys around 14 years, girls about 12 years), is associated with increased incidence of spinal pain.²⁵
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46 Since previous studies noted discrepancies between children's and parents' reports, when it comes to the
47
48 child's experience of pain.²⁶ Therefore, it was decided not to use the parents as a proxy measure, and data
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50 was collected directly from children to create a more reliable account of the discussed issues.¹⁶ Sample size
51
52 was not determined a priori but interviews were conducted until data saturation at each age and well-being
53
54 strata was reached.
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58 The Young Spine Questionnaire (YSQ)²⁷ was administered to identify children suffering from non-specific
59
60 spinal pain. Since more than 80% in this group report some degree of non-specific spinal pain, most of it

1
2 trivial, inclusion was limited to children with non-trivial pain as described in Table 1.²⁸ In addition, the
3
4 children filled in the Kid-Screen 10²⁹ as a measure of mental well-being, as it is unknown whether a child's
5
6 mental well-being influences the experience of non-specific spinal pain. We categorized the children's well-
7
8 being into three groups following the instruction and the predefined groups (low, normal and high level of
9
10 well-being) from the Kid-Screen Group.²⁹
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14 The interviewees were selected from the group of children who fulfilled the inclusion criteria listed in Table
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16 1 and according their level of well-being (see Data collection).
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21 ---- Table 1 ----
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25 *Participants*
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27 All participants were recruited from two Danish public schools in two different regions of the country.
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29 Children with non-specific spinal pain between the ages of 9 and 12 were included.
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33 *Pilot procedures*
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35 To ensure that all practical procedures, including the recruitment strategy, were suitable for the study, these
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37 were tested in a pilot test conducted at a Danish public school in one region of the country and included four
38
39 children, one of each age (9-12 years) and representing both sexes as well as all three well-being groups.
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44 *Data collection*
45

46 Prior to data collection, information material about the study was distributed to the teachers, children and
47
48 their parents. In addition, the teachers in the 3rd to 6th grade (3rd grade age range: 8.5 to 9.5 years; 6th grade
49
50 age range: 12.5 to 13.5 years) set aside time during teaching hours to fill out the YSQ²⁷ and the Kid-Screen 10
51
52 ²⁹, including questions about age and gender. This allowed identification of eligible children with non-trivial
53
54 spinal pain according to the inclusion criteria outlined in Table 1. The completed YSQ-forms from the
55
56 eligible children were divided into three piles, representing three levels of well-being, for each age group, i.e.
57
58 12 piles. The piles were shuffled, and the interviewer drew consecutive interviewees from the 12 piles to
59
60 optimize equal distribution of age and well-being strata. The selected children were invited for interviews,

1
2 and their parents received additional information about the objectives and procedures for the interview and
3
4 returned a signed informed consent form. On the day of data collection, the children provided verbal assent
5
6 to participate and were able to opt out at any time during the selection procedure and in the interview. Before
7
8 conducting each interview, the answers on the YSQ were examined by the interviewer.
9

10
11
12 One of the authors (ABS) conducted all interviews from January 2017 to March 2017 within a week after the
13
14 child had completed the questionnaires. The face-to-face approach was chosen to allow co-creation of
15
16 meaning by reconstructing perceptions of experiences and events related to non-specific spinal pain.³⁰ A full
17
18 body drawing, and the revised faces pain scale (FPS-R)³¹ were initially used to ensure that the painful area
19
20 pertained to the spine and the intensity of the pain.³² Otherwise the children were free to express themselves
21
22 freely during the interview.
23

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27 A maximum of two interviews were carried out per day, and all interviews were recorded and transcribed for
28
29 analysis prior to conducting further interviews. The interviews were carried out at the participants' schools
30
31 during normal school hours. Participants were told that they were free to terminate the interview at any time.
32
33

34 35 *Data analysis*

36
37 The transcription was performed by ABS and coding was carried out inductively by two authors (ABS and
38
39 CM) to facilitate the emergence of general themes of key concepts relevant to non-specific spinal pain. A
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41 thematic approach using five steps (data familiarisation, generating initial codes, searching for themes,
42
43 reviewing themes and defining and naming themes) as outlined by Braun & Clarke was used.³³ Themes
44
45 relating to children's experience of non-specific spinal pain and the consequences thereof were then
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47 identified among all the authors across the codes. The process of the data collection and analysis is shown in
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49 Figure 1.
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55 ---- **Figure 1** ----
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1
2 Coding and analysis were carried out using the Atlas Ti computer assisted qualitative data analysis software
3
4 package version 1.0.49, and data were treated confidentially and anonymized in connection with the
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6 transcription.
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10 **Focus group study**

11
12 A further focused exploration and elaboration of the codes and key concepts identified in the interview study
13
14 was performed in a focus group study.³⁴ The express purpose was to ensure that respondents consistently
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16 include and exclude the same features of the construct. This process required significantly more prompting
17
18 from the investigators and was therefore best accomplished through focus group interviews. These were
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20 conducted by three of the authors (ABS, HHL and LH) on the largest of the two schools.
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25 *Participants*

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27 Based on the questionnaires from the first part of the study, four children, who had not been interviewed
28
29 previously, were selected from each grade (3rd-6th) based on the criteria in Table 1. The participants were
30
31 divided into two focus groups comprising eight children in each group. New information material and
32
33 parental consent forms were distributed, inviting the children to a focus group discussion at the school.
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38 *Materials*

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40 We developed multiple sets of cards with one code written on each card. Each set of cards included all the
41
42 identified codes from the interview study. An A3 poster was developed by the author group for each theme
43
44 including a statement describing the theme and one or two visual drawings. Each theme statement was
45
46 carefully selected from the codes developed in the interview study. For example, the statement for the ‘Sport
47
48 and play’ theme was ‘I cannot do the same as my friends’. The drawings were simple illustrations reflecting
49
50 the theme. They were also inspired by the codes, and in the example of the ‘Sport and play’ theme, they
51
52 included a football with a football goal and a basketball with a basketball stand and net. Sticky tacks were
53
54 provided to the children during the phase of placing the cards on the theme posters.
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59 *Exploration and elaboration of the codes and themes*

1
2 Children with signed informed consent were gathered for a three-hour session at the school. First, the
3
4 children were divided into two focus groups (8 pupils in each group) each receiving sets of cards with all the
5
6 codes. Each focus group was managed by two author team members, one giving the pupils instructions and
7
8 answering questions and the other observing interactions and taking notes on discussed topics and issues.
9
10 Each member of the focus group was asked to sort the cards into two piles: one with relevant (i.e. this
11
12 applied to me, when I had the pain) and one with irrelevant (i.e. this did not apply to me, when I had the
13
14 pain) in relation to their experience of non-specific spinal pain. This was followed by a break, allowing the
15
16 researchers to discuss the observations noted by the observers. Following this, all the codes were discussed
17
18 first within the two focus groups and subsequently in a plenary group involving all the children with the
19
20 researchers initiating peer-to-peer discussions. The decision to form a larger plenary group was to engage
21
22 pupils in peer-to-peer discussions with other pupils allowing them to articulate their own and new ideas
23
24 about the codes. Next, the themes which emerged through the analysis of the interview study were presented
25
26 and explained to the children, followed by examples of possible theme-categorizations of each code. Finally,
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28 the A3 posters reflecting each theme were placed on the wall, and the children placed their cards with
29
30 relevant codes on the poster they considered to be best fitting.
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36 **Code mapping to the ICF and comparison to adult questionnaires**

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38 All the identified codes were assigned corresponding categories using the ICF for comparison with
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40 commonly used questionnaires designed for adults. The ICF framework was chosen because it allows direct
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42 comparison between questionnaires by assigning codes from the framework to individual items, indicating
43
44 similarity of content.³⁵ Two researchers (LH and HHL) assigned ICF categories independently to each code
45
46 using the linking rules defined by Cieza et al.^{36 37} The assigned ICF categories from the two researchers were
47
48 compared. If minor classification disagreements occurred (at the second or third level), a consensus-based
49
50 process was implemented. In case major disagreement (at the component or chapter level), an external expert
51
52 who has previously used the ICF extensively was consulted.
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57 Our ICF categories were compared to the content of questionnaires commonly used to assess the
58
59 consequences of low back pain (LBP) and neck pain (NP) in adults to elucidate whether the content of adult
60
questionnaires would cover what children consider relevant.

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4 We chose to compare our codes to the two most commonly used low back specific questionnaires: the
5
6 Oswestry Disability Index, and the 24-item Roland-Morris Disability Questionnaire,³⁸ and three commonly
7
8 used neck specific questionnaires: The Neck Disability Index, the Neck Bournemouth Questionnaire, and the
9
10 Neck Pain and Disability Scale.³⁹ ICF categories for each questionnaire were derived from published
11
12 literature.³⁹⁻⁴²
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15

16 **Patient and public involvement**

17
18 The public was not involved in the design, conduct, reporting, or dissemination of this study.
19
20
21

22 **Ethical approval**

23
24 The study was approved by the Danish Data Protection Agency (J.nr. 2015-57-0008) but approval was not
25
26 required from the local ethics committee according to Danish law.⁴³
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30
31 A reporting checklist for qualitative studies was used to ensure adherence to the key elements when reporting
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33 qualitative studies.⁴⁴
34
35

36 **RESULTS**

37 **The interview study**

38 *Pilot procedure*

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40 The practical procedures involved in recruiting the children, receiving informed consent and setting up an
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42 interview were tested on four children in one public school. This resulted in minor adjustments to the
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44 procedures of recruiting the children and who to communicate with at the school. Data from the pilot
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46 procedure were not included in main analyses.
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51 *Participants*

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53 In the two schools combined, 338 children completed the YSQ and the Kid-Screen 10, and 199 of these
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55 fulfilled all inclusion criteria (41%). After stratification according to age and mental well-being, 36 children
56
57 were invited for interviews and a total of 20 children accepted and were interviewed (one interview was
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59
60

1
2 excluded due to the exclusion criterion ‘musculoskeletal diagnosis’). Nine girls and ten boys from 9-12 years
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4 spread across the three well-being strata were included. The characteristics of the interviewees are shown in
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6 Table 2.

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---- Table 2 ----

Data collection and saturation

The interviews lasted from 15 to 30 minutes, and no participants chose to terminate the interview. Data saturation was achieved at interview number 16. To investigate a potential geographic variation, interviews 17-19 were conducted at a school in another region of Denmark, but no new aspects came up. No noteworthy differences were found between ages, gender, geographic location or well-being levels.

Codes and emerging themes

A total of 21 individual codes were created and examples of key quotes for each code can be seen Table 3. The references are shown as ‘#Y:Z’ where Y refers to the individual and Z to the quote number.

---- Table 3 ----

Across the 21 codes, five themes emerged in relation to the children’s experiences of living with non-specific spinal pain. The five themes were: ‘Sports and play’, ‘Axial loading’, ‘Coping strategies’, ‘Mood changes’ and ‘Pain anxiety’. Table 4 provides an overview of the thematic analysis, and the codes represented in the five themes.

---- Table 4 ----

Each of the five themes are presented and described in detail below with examples of quotes noted in parentheses.

(a) Sports and play

1
2 Physical limitations, such as staying away from sports or not being able to play with friends were one of the
3
4 main complaints for the children (#17:2). In general, the children reported frustration and concern when they
5
6 were unable to participate in sports and activities at the same level as their friends (#8:5). Some of the
7
8 children tried to find a way to participate, either by communicating their pain (#3:47), or by finding another
9
10 role in the game which was less physically demanding (#10:6). Some children would isolate themselves or
11
12 find alternative solutions, e.g. by playing with another group of children engaging in less physically
13
14 demanding games or sports (#5:73).

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18
19 *(b) Axial loading*

20
21 Axial loading was reported to be a risk factor for developing as well as maintaining spinal pain. Jumping on
22
23 a trampoline was stated as a triggering cause of pain by a significant number of the interviewees (#7:13).

24
25 Many reported that they felt unable to jump on the trampoline as it increased their spinal pain (#7:8).

26
27 Walking with a heavy school bag (#4:15), playing computer games (#5:50), or sitting down in school (#9:2)
28
29 were reported as other causes for an increase in spinal pain. It was also reported that the ability to
30
31 concentrate was affected by spinal pain, when sitting down for longer periods e.g. in school (#9:2).

32
33
34
35
36 *(c) Coping strategies*

37
38 Many children tried to find a logical explanation for the cause of their pain experience (#13:16) to
39
40 understand or cope with their limitations and frustrations. A group of children reported that they didn't know
41
42 how to get pain relief (#18:6). This contrasted with a larger group of the children, who tried to help
43
44 themselves either actively or passively. Examples of active distraction strategies were playing with friends
45
46 (#5:44), doing sports (#2:22), going to school (#19:22), exercises (#12:18) or stretching the back (#15:18).
47
48 Examples of passive strategies to reduce spinal pain could be lying down (#13:27), restricting movements or
49
50 avoiding specific movements (#5:54), indicating a certain movement anxiety. A group of children even
51
52 reported that they were extremely aware of what they carried on their backs, e.g. heavy school bags (#2:107)
53
54 (this was also noted in the axial loading theme, above).

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58
59 A cognitive approach was reported by some children whereby they tried to focus on something else to make
60
the pain disappear (#11:30). A couple of the children even said that they would hurt themselves e.g. by

1
2 pressing a hand to the back to reduce the spinal pain (#2:87). In general, the children reported less pain when
3
4 they were distracted by physical, psychological or social inputs.
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8 Some of the children were afraid of being misunderstood and therefore talked about their spinal pain
9
10 primarily with people who had themselves suffered from spinal pain (#10:3). The children most frequently
11
12 reported that they talk primarily with their parents (#19:14), and secondarily with friends (#10:3) or sports
13
14 coaches (#17:14) about their spinal pain.
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18 19 *(d) Mood changes*

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21 Nearly all children indicated frustration and incomprehension about their spinal pain (#5:61). A large group
22
23 of children expressed a relation between their mood and the spinal pain, especially feeling sad and frustrated
24
25 due to pain (#3:48). Some children also implied that their negative mood was caused by lack of sleep, and
26
27 that reduced sleep was due to excessive back pain (#3:48). A few reported difficulties concentrating when
28
29 experiencing spinal pain (#19:12). Although a good mood could reduce the pain, the children often
30
31 continued to feel the pain, and some were even afraid to show it in class or to teammates (#2:79).
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35 36 *(e) Pain anxiety*

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38 A group of children reported no problems related to their spinal pain. There was some indication that they
39
40 coped with the pain as if it was a cold or stomachache, which would go away by itself (#15:23). However,
41
42 another group of children articulated some level of concern when experiencing spinal pain. There was a large
43
44 variation in how often, how much and which aspects concerned the children. Some worried that they could
45
46 not keep up with school work and that absence would influence their future lives (#10:30), while others
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48 feared they would get the same physical limitation as they knew from their parents (#5:62). Some children
49
50 were extremely worried and reported that they could hardly cope due to the pain intensity combined with
51
52 their thoughts and concerns about the pain (#7:20). The children who were concerned indicated that they
53
54 were more careful regarding their backs, even when not experiencing spinal pain (#19:19). Some of the
55
56 children were even afraid to become isolated from their friends if they told them about the pain (#2:97).
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Group differences

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2 A comparison of the emerging themes across age groups, gender and well-being did not reveal any
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4 differences among the groups.
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8 *Salient issues*

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10 Two issues were not included as codes in Table 3, since they did not describe consequences of pain. ‘No
11 limitations’ represented children that were not affected or limited by spinal pain in everyday life despite
12 fulfilling the inclusion criteria for spinal pain, and ‘Cause not known’ was important to some children but
13 has not been explored further in this study because it refers to aetiology.
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20 The analysis also identified four codes which described the area of consequences with the most impact on
21 the child (i.e. movement, pain, psychological factors and social limitations). Each code commenced with
22 ‘Worst is...’ and arose from specific questioning and were therefore not assigned to a specific theme.
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29 **The focus group study**

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31 Sixteen children participated in two focus groups and plenary session with all four grades represented (3rd –
32 6th). All the previously identified codes were chosen by at least two children as being relevant, with nine of
33 the 21 codes being chosen by five or more participants. It was possible to include all children in the follow-
34 up discussion, but despite a long and lively discussion, no new codes emerged. There was a large uncertainty
35 among the children about categorizing the codes into themes, reflecting the complexity of the task and that
36 some codes are represented in more than one theme.
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46 **Code mapping to the ICF and comparison to adult questionnaires**

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48 Of the 21 identified codes, five were classified into the ‘Body functions’ component (one shared with the
49 ‘Personal factors’ component), eight into the ‘Activities and participation’ component (one shared with the
50 ‘Body structures’ component), one as an ‘Environmental factor’, and four as ‘Personal factors’. Five codes
51 were not classifiable, whereof four related to the specific question: ‘What is worst?’ (codes 18-21). Some
52 codes could be assigned more than one ICF category, and therefore the final number of ICF categories was
53 24. According to the categorization rules by Cieza et al., ICF category b280 (sensation of pain) should have
54 been used for several of the codes. However, ‘sensation of pain’ is indirectly related to all the codes, since
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1 they refer to non-specific spinal pain, and therefore we chose only to use b280 for 'pain intensity', which is a
2 direct expression of the pain sensation.^{36 37} The ICF categories have been added to Table 3.
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8 The items in the adult questionnaires were categorized within the ICF components of 'Body functions', and
9 'Activities and participation', whereas 'Personal factors', which the children found very important, were not
10 covered (Table 5). A total of 10 out of 24 ICF categories (42%) were covered by at least one adult LBP
11 questionnaire whereas nine (38%) were covered by adult NP questionnaires. Three categories in 'Body
12 functions' (sleep, emotional function, and sensation of pain) and two in 'Activities and participation' (lifting
13 and carrying, and sports) were included in most questionnaires whereas 11 ICF categories were not included
14 in any of the five adult questionnaires (one in 'Body functions', five in 'Activities and participation', one in
15 'Environmental factors', three 'Personal factors' and one 'not classifiable').
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27 The content of the children's codes and the content of the adult questionnaire items within each ICF category
28 differed considerably at times. For example, the ICF category of 'Play' (d9200) related to a physical
29 limitation in the children (e.g. staying at home, not being able to do the same activities as one's peers)
30 whereas it related to restrictions in recreational activities (i.e. 'Reading', item 4 in the Neck Disability Index;
31 'Family activities', item 3 in the Neck Bournemouth Questionnaire; 'Interference with social activities', item
32 8 in the Neck Pain and Disability Scale) in the adult questionnaire items.
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42 ---- Table 5 ----

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46 DISCUSSION

47 Precise conceptualization of a target construct is critical to the validity cascade, but also ultimately the
48 application of a questionnaire.⁴⁵ Therefore, the key contribution of this investigation lies arguably in the
49 identification of the consequences of living with non-specific spinal pain in a population of 9-12-years old
50 children. It has previously been reasoned and observed that a poorly conceptualized target construct will
51 inevitably result in measurement error.^{21 34} As such, it was the express objective in this investigation to elicit
52 detailed descriptions of non-specific spinal pain experiences from a group of 9-12-year old children
53 resembling the population a future instrument will be applied to. Thus, the focus of this study is the
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1
2 development of a new questionnaire, but nevertheless results can be used broadly to inform researchers and
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4 clinicians working with children with non-specific spinal pain.
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8 The interviews revealed 21 codes, of which 17 could be classified into five themes: 'Sports and play', 'Axial
9
10 loading', 'Coping strategies', 'Mood changes' and 'Pain anxiety'. Several codes were represented in more
11
12 than one theme, and we observed the physical experience in the 'sport and play' theme as the dominant
13
14 cognitive hub through which this group of children access and link the psychological and social domains.
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16 We also observed that the anxiety at times could appear counterproductive and possibly add to a negative
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18 trajectory of pain. We therefore recommend that this is addressed explicitly in future programmes for
19
20 treatment and prevention of non-specific spinal pain in children.
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25 Two issues were not included in the identified codes, although appearing several times. The first was 'no
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27 limitation', demonstrating the important fact that some children do not experience any limitations at all,
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29 despite fulfilling the inclusion criteria of non-specific spinal pain 'sometimes or often' and three or more on
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31 the FPS-R. This could indicate that some children are capable of handling pain of moderate intensity and
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33 frequency without it causing any physical or psychosocial limitations. Another reason could relate to
34
35 uncertainty regarding the validity of self-reported pain in children⁴⁶. The other issue was 'cause not known'
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37 reflecting the children's desire to know why they had pain. This was excluded as it refers to aetiology of the
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39 pain. It did, however, reflect a strong desire among the children to understand their pain, although the
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41 interviewer attempted to focus on the consequences of it. This desire was also obvious during group
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43 discussions and may partly explain the prominent pain anxiety experienced by the children.
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48 The study also revealed four areas of impact as a result of the non-specific spinal pain. These arose from
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50 direct questioning ('What is worst?') and were limitations in movement, pain, psychological factors and
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52 social limitations. Distinction between these areas are important from a clinical point of view as enquiring
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54 about them have the potential for the clinician to direct treatment, or anxiety-reducing advice and support, to
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56 a specific domain.
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2 When comparing the identified codes to the content in adult questionnaires, only approximately 40% of the
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4 ICF categories were covered and this related mainly to the component of 'physical functioning' which is
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6 recommended as a core outcome for adults with low back pain.¹³ Psychological and social factors were much
7
8 more prominent to the lived life of children and pain anxiety was a dominant theme with many children
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10 expressing fear of future pain. Therefore, it appears clear, that questionnaires developed for adults are not
11
12 adequate for paediatric populations.
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16 **Strength and limitations**

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18 This is the first study using a formal qualitative approach to explore the consequences of non-specific spinal
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20 pain in children aged 9-12. A limitation was that the plenary focus group consisting of 16 children was quite
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22 large, however we experienced no apparent issues with managing the interaction between participants.
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24 Furthermore, we believe our study findings are transferrable to settings with a similar school structure and
25
26 sociodemographic composition, typically the Scandinavian countries. However, the results may not be
27
28 generalisable beyond the Scandinavian culture as pain narratives may be influenced by socio-cultural
29
30 factors.⁴⁷ Therefore, we recommend that studies exploring pain narratives in this age group are carried out in
31
32 other cultures and the results compared to ours.
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37 In addition, the findings are only applicable to children in a narrow age range from 9 to 12 years. We advise
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39 caution using the results in younger or older children as the experienced consequences of non-specific spinal
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41 pain may differ substantially. Further studies in adolescents are warranted.
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45 **CONCLUSION**

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47 For some children, non-specific spinal pain sets off a cascade of negative consequences, that affects their
48
49 everyday life in five key domains. 'Sport and play' and 'axial loading' correspond particularly well with the
50
51 'physical function' domain recommended for the adult populations. Interestingly though, although the
52
53 overall categories identified were similar to those found in adult populations, individual codes for the
54
55 children differ significantly from their adult counterparts. Our results confirmed that the perceptions of the
56
57 consequences of non-specific spinal pain in children aged 9-12 years is complex, but also that some children
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1
2 do *not* experience any consequences despite reporting non-trivial spinal pain. We recommend the identified
3
4 themes and codes serve as a starting point for the development of a new questionnaire.
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For peer review only

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Competing interests

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Author contributions

HHL and LH conceived the study and AS, HHL, CM and LH participated in the design and coordination of it. AS carried out the interviews and the coding of the material, and HHL, AS and LH carried out the confirmatory study. HHL and LH performed the coding and comparison to the adult questionnaires. HHL, AS, CM and LH drafted the manuscript and all authors read and approved the final manuscript.

Availability of data and materials

Data are not available due to legal (GDPR) and ethical restrictions.

Tables

Table 1. Inclusion and exclusion criteria.

Inclusion criteria
<ul style="list-style-type: none"> • Children 9-12 years of age with non-specific pain in one or more parts of the spine • A pain intensity of at least face number three on the revised Faces Pain scale in the YSQ* • Children indicating having non-specific spinal pain 'sometimes' or 'often' in the YSQ • Written permission to participate in the project from a parent/guardian
Exclusion criteria
<ul style="list-style-type: none"> • Children who do not understand or speak Danish • Children with diagnosed musculoskeletal disorders (e.g. Muscular Dystrophy, Juvenile Osteoporosis, Congenital Myopathy)

* YSQ, Young Spine Questionnaire

Table 2. The distribution of all participants according to age, gender and well-being.

	Well-being	9 years	10 years	11 years	12 years	13 years	Total
Girls spinal pain \geq 3 FPS-R	Low	6 (0)	10 (0)	6 (0)	2 (1)	0 (0)	24 (1)
	Normal	14 (1)	23 (1)	18 (2)	16 (2)	9 (0)	80 (6)
	High	2 (0)	1 (1)	0 (0)	3 (1)	0 (0)	6 (2)
Boys spinal pain \geq 3 FPS-R	Low	3 (1)	5 (0)	3 (1)	1 (0)	0 (0)	12 (2)
	Normal	10 (0)	15 (2)	17 (4)	12 (2)	8 (0)	62 (8)
	High	0 (0)	1 (0)	1 (0)	13 (1)	0 (0)	15 (1)
Total spinal pain \geq 3 FPS-R		35 (2)	55 (4)	45 (7)	47 (7)	17 (0)	199 (20)

Note: Shows the distribution of eligible participants with non-specific spinal pain equal to or more than 2 on the FPS-R, who also reported spinal pain 'sometimes' or 'often' stratified according to their well-being. The number in () is the number of participating interviewees.

FPS-R, revised Faces Pain Scale

Table 3. Codes, key quotations and corresponding ICF categories

Codes	Key quotations	Reference	ICF category
Body functions			
1. Affected sleep	'I remember having difficulties falling asleep, as I could not lie down properly. I had to fall asleep as fast as possible, in order not to feel the pain when I turned, as that woke me up, (I: Have you tried waking up due to pain?) Yes.'	#19:4	b134
2. Worrying about spinal pain	'Well, I'm afraid I can't do the same things as other children, and then I can't play with them. It is also really difficult to bicycle home and everything ...'	#1:55	b152
3. Pain intensity	'...It just stops like, I almost can't breathe ...'	#5:55	b280
4. Difficulties to define the pain*	'... One night, I was just about to go to bed, my mom asked if I was feeling alright, I told her that my back really hurt. She then said I should see a chiropractor. ... It was hard to find out where it hurt so much, which was really annoying as I could not tell my mom, or the chiropractor.'	#19:7	b280 b780 pf
Activities and participation			

5. Talking with parents	‘Yes, I talked with them as I had to, and you should know that you need to be talked with...because it helps. It helped me a lot to talk with my parents about the pain’	#19:14	d350 d7601
6. Talking with friends	‘Sometimes, I tell that I have pain in my back, so I can’t play too wildly ...’	#7:23	d350 d7500 d7504
7. Do not want to talk with others about the pain	‘... I have not talked with them ... I just wanted to keep it to myself as I thought it could be really uncomfortable if other people knew that I have back pain. ... It is just something one have, and they don’t like to let other people know ...’	#19:15	d350 d710
8. Maintaining static postures	‘... You sit down for many hours and when standing up or move a bit, it starts hurting really really bad ...’	#10:17	d4150 d4153 d4154 d4155
9. Spinal load	‘.. it also hurts when I carry my bag, and the pain increases... (I: Is there a difference in carrying light and heavy stuff?) Yes, often if I have to carry a heavy bag, which gives me a headache ‘	#7:2	d430
10. Social limitation	‘Sometimes when I am asked if I can play, I say no, I just want to go home and rest. I don’t say that I have back pain, I just say I think that I want to go home and rest.’	#5:66	d750
11. Physical limitation**	‘... I can’t do the same activities, e.g. running, as the boys,...’	#3:44	d9200 d9201 d9205 b7
12. Reduction in participation	‘... I have had to stay home because I almost couldn’t stand up ...’	#10:12	d9200 d9201 d9205
Environmental factors			
13. Treatment tried/not tried	‘Yes, a lot. Often I go to my mom’s chiropractor, as he puts anything in place, and stuff like that.’ ‘No, not really. My mom tried to give me massage when I came home from handball as she knows where it hurts, because she is a nurse and have worked at a hospital.’	#9:8 #10:15	e580
Personal factors			
14. Improving factors	‘We have put less in my bag, so I only have to carry the most necessary stuff, and not even a pencil more (I: Can you feel that it helps?) Yes, it helps me, because the bag is less heavy than before, and I have less pain...’	#2:107	pf
15. Worsening factors	‘... I will not run as much as I normally do. (I: Why not?) as I can feel that it starts to hurt more.’	#14:1	pf
16. Strategies to avoid pain	‘When I sit down, then I first have to sit on my hands, as this somehow reduces the pain. I will then let go, which soothes the pain somewhat.’	#10:20	pf

Not classifiable			
17. Cause of pain known/unknown	‘It will hurt in my back, if I jump too much on the trampoline.’	#7:8	nc
	‘I actually don’t think I know why I had pain. Maybe it was because I had just made a wrong movement, or something with my neck while sleeping or something. I don’t really know.’	#17:4	
18. Worst is movement	‘The very worst, I think the worst, is to jump rope ... because I have to jump up and down, up and down.’	#3:54	nc
19. Worst is pain	‘It just hurts really bad - I can’t even go to the toilet, even though I have to (I: Is that because it hurts to walking to the toilet?) [Participant nodding].’	#1:17	nc
20. Worst is psychological factors	‘I think it is the feeling you have in the back, as it can make a bad day worse.’	#15:21	nc
21. Worst is social limitation	‘It must be that I am unable to do the same as all of my friends – that must be the worst as I feel a bit left out.’	#10:16	nc

Note: pf, personal factor; nc, not classifiable

* The code ‘Difficulties to define the pain’ appears once but has been classified as both ‘Body functions’ and ‘Personal factors’.

** The code ‘Physical limitation’ appears once but has been classified under ‘Activities and participation’ and ‘Body functions’.

Table 4. Thematic analysis.

Themes	Codes
‘Sports and play’	Pain intensity (b) Worrying about spinal pain (b) Physical limitation (d, s) Reduction in participation (d) Talking with friends (d) Social limitation (d) Strategies to avoid pain (pf)
‘Axial loading’	Pain intensity (b) Spinal load (d) Maintaining static postures (d) Social limitation (d) Cause of pain known/unknown (nc) Worsening factors (nc)
‘Coping strategies’	Difficulties to define the pain (b) Worrying about spinal pain (b) Physical limitation (d, s) Talking with parents (d) Talking with friends (d) Do not want to talk with others about the pain (d) Spinal load (d) Social limitation (d) Reduction in participation (d) Improving factors (pf) Strategies to avoid pain (pf) Treatment tried/not tried (e)

	Cause of pain known/unknown (nc) Worsening factors (pf)
'Mood changes'	Affected sleep (b) Worrying about spinal pain (b) Talking with parents (d) Social limitation (d) Improving factors (pf)
'Pain anxiety'	Worrying about spinal pain (b) Physical limitation (d, s)

Note: The four codes 'Worst is...' are not included in the themes as they arose from a specific question. Some of the codes appears in several of the themes. The main ICF component are in (): b, 'Body function'; d, 'Activities and participation'; e, 'Environmental factors'; s, 'Body structure'; pf, 'Personal factors'; nc, 'Not classifiable'.

Table 5. Comparison of ICF categories found in children aged 9-12 to what is covered in commonly used adult low back and neck pain questionnaires.

Category	ICF Description	Low back pain questionnaires		Neck pain questionnaires		
		ODI ^{40 41}	RMDQ ⁴⁰	NDI ^{39 42}	NBQ ^{39 42}	NPDS ^{39 42}
Body functions						
b134	Sleep function	+	+	+		+
b152	Emotional function	+	+		+	+
b280	Sensation of pain	+	+	+	+	+
b7	Neuromusculoskeletal and movement-related functions					(+)
b780	Sensations related to muscles and movement functions					
Activities and participation						
d350	Conversation					
d430	Lifting and carrying objects	+	+	+	+	
d710	Basic interpersonal interactions					
d750	Informal social relationships	+				+
d4150	Maintaining a lying position	+				
d4153	Maintaining a sitting position	+	+			
d4154	Maintaining a standing position	+	+			
d4155	Maintaining head position					
d7500	Informal relationships with friends					
d7504	Informal relationships with peers					
d7601	Child-parent relationships					
d9200	Play			(+)	(+)	(+)
d9201	Sports	+		(+)	(+)	(+)
d9205	Socialising	+			(+)	+
Environmental factors						
e580	Health services, systems and policies					
Other*						
pf	Improving factors					
pf	Worsening factors					
pf	Strategies to avoid pain					
nc	Cause of pain known/unknown					

Note: As Wang (2012) and Wiitavaara (2018) both include the ODI, the ICF classifications have been combined to include all ICF categories used.

(+) Covered with an ICF category either at a higher or lower level; * Category wordings of pf and nc are the codes from this study. pf, personal factor; nc, not classifiable; ODI, Oswestry Disability Index; RMDQ, Roland Morris Disability Questionnaire; NDI, Neck Disability Index; NBQ, Neck Bournemouth Questionnaire; NPDS, Neck Pain and Disability Scale.

Figures

Figure 1. Data collection and flow of analyses.

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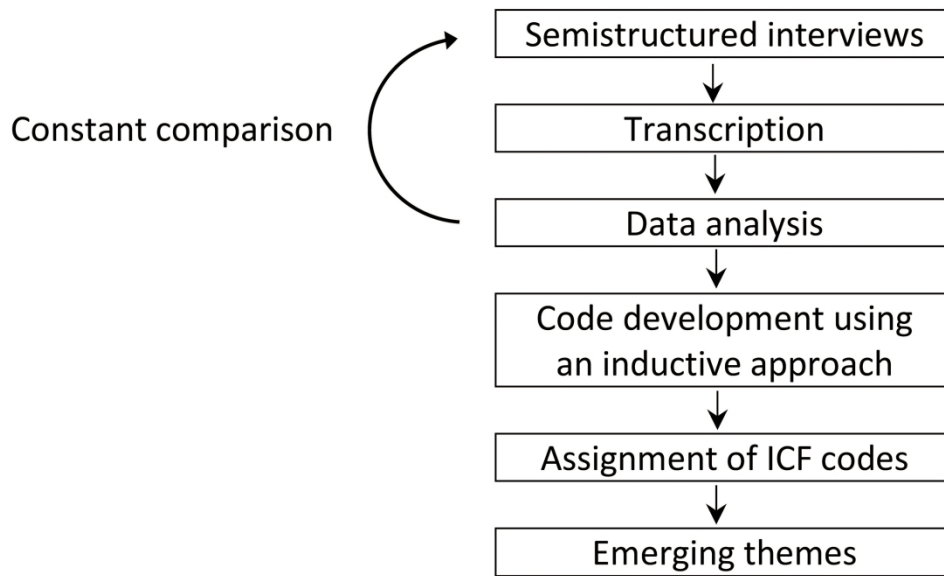


Figure 1. Data collection and flow of analyses.

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