

# BMJ Open Experiences of a non-clinical set of adolescents and young adults living with persistent pain: a qualitative metasynthesis

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**To cite:** Fegran L, Johannessen B, Ludvigsen MS, *et al.* Experiences of a non-clinical set of adolescents and young adults living with persistent pain: a qualitative metasynthesis. *BMJ Open* 2021;**11**:e043776. doi:10.1136/bmjopen-2020-043776

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-043776>).

Received 13 August 2020  
Revised 16 March 2021  
Accepted 28 March 2021



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## ABSTRACT

**Purpose** Around 15%–30% of adolescents and young adults (AYAs) experience persistent or chronic pain. The purpose of this study was to synthesise evidence from qualitative primary studies on how AYAs in a non-clinical population experience living with persistent pain.

**Method** A qualitative metasynthesis guided by Sandelowski and Barroso's guidelines was used. The databases Medline, Embase, Cinahl, PsycINFO, Mednar and ProQuest were searched for studies from 1 January 2005 to 15 February 2021. Inclusion criteria were AYAs aged 13–24 years with first-hand experience of living with persistent, recurrent or episodic non-clinical pain in any body site. Pain associated with a medical diagnosis, malignant diseases, medical procedures or sport activities was excluded.

**Results** Of 2618 screened records, data from nine studies conducted in a Western cultural context including 184 participants (127 female and 57 male aged 11–28 years) were analysed into metasummaries and a metasynthesis. Headaches was the most focused pain condition (n=5), while three of the studies did not specify type of pain. The participants' experiences were characterised by (1) juggling pain with everyday life; (2) exploring sources of information to manage pain; (3) AYAs' use of medication to find relief and (4) non-pharmacological strategies for pain relief.

**Conclusion** These AYAs experience of how pain influences everyday life, and their striving to find relief from pain by support from family, friends, professionals and the Internet should be strongly respected. Public health nurses and other healthcare professionals encountering AYAs need to respect their pain experiences, and to support them in healthy coping strategies. Further studies on this issue are needed, especially research focusing on AYAs pain in exposed populations and AYAs from non-Western cultures.

## INTRODUCTION

In recent years, it has been recognised that pain comprises a common and growing health problem among adolescents and young adults (AYAs). The prevalence varies in non-clinical populations defined as a population without a clear clinical diagnosis, or not recruited from a clinical context as, for example, a pain

## Strengths and limitations of this study

- The use of a robust and transparent review method revealed that, despite a vast amount of research on this topic, individual adolescents and young adults (AYAs') experiences are difficult to identify and extract.
- The qualitative approach is an important contribution to this research field by providing a deeper understanding of why and how AYAs strive to find relief for their pain.
- Despite the challenge of identifying AYAs' voices, synthesising data from a sample of 184 AYAs from a non-clinical setting has contributed to a novel understanding of their experiences when living with persistent pain.
- The lack of studies providing data from minority cultures, exposed populations or studies from countries outside North America or Europe is a limitation.
- Exclusion of studies describing clinical pain, procedure pain and pain in connection with sports could possibly have concealed aspects of pain experiences relevant to understand the complexity of AYAs pain.

clinic. However, research has shown a trend towards a high and increasing prevalence of persistent or chronic pain, varying from 20% to 35% in different studies.<sup>1–6</sup> Such pain can lead to significant interference in daily functioning and daily life, and is associated with poor sleep, stress, impaired school/college functioning and absenteeism.<sup>7–10</sup> Studies also show that more female than male AYAs report pain; moreover, living with pain affects female AYAs more negatively.<sup>4 11 12</sup> Further, pain problems can negatively influence a young person's quality of life and health.<sup>4 9 13</sup> Experiencing pain in adolescence is related to pain problems later in adulthood, and research indicates that pain problems might also have serious long-term consequences.<sup>14–16</sup>

Subjectivity is at the core of the experience of pain as reflected in various definitions.



McCaffery's well-known definition of pain often cited in nursing studies describes pain as: 'Pain is whatever the experiencing person says it is, existing whenever he says it does'.<sup>17</sup> According to International Association for the Study of Pain (IASP) nomenclature, pain is always subjective, and the IASP definition recognises the central role of emotions in defining pain as 'an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage' (Merskey, p.24)<sup>18</sup> These definitions highlight the importance of accepting the person's perception and experience of pain. Pain is a complex phenomenon and can be a symptom of underlying problems reflecting several psychological, social and physical factors.<sup>4 19 20</sup> Adolescence is a vulnerable period in life between childhood and adulthood, and can be challenging with respect to developmental tasks, independence from caregivers, social development and peer relationships.<sup>21 22</sup> However, this period of development also provides an opportunity for young people to develop positive health behaviours to improve their functioning and to prevent future pain-related problems.<sup>5 23 24</sup>

Previous studies have given us knowledge of the prevalence of pain and its associated factors; however, pain among adolescents is still an understudied topic, especially in non-clinical populations. Few qualitative studies explore adolescents' personal experiences of living with pain, how they cope with it, and how it can influence their emotional and physical functioning. Research suggests that they use methods familiar to them to manage their pain.<sup>25 26</sup> Differences in coping might be related to each adolescent's personality and coping style.<sup>27</sup> In qualitative studies of young people with chronic pain, different coping strategies were identified, and coping strategies were shown to be influenced by family, friends and attitudes to pain.<sup>28 29</sup>

Some qualitative studies have shown that female AYAs are more likely to talk to friends about pain problems than are male AYAs, and to use pain medication as a coping strategy.<sup>30</sup> Moreover, many parents were unaware of their adolescent's pain, and the adolescents did not speak to their parents about their pain experience.<sup>3 13</sup> A Swedish study of adolescents and their use of over-the-counter (OTC) medications revealed that OTC drug use was significantly influenced by parents and peers.<sup>31</sup> Studies from Norway have shown that adolescents have a

high frequency of use of OTC medications and use them as a coping strategy.<sup>28 29</sup>

To be able to help adolescents to cope with pain and develop prevention strategies, it is important to improve our understanding of adolescents' experience with pain, and how they cope with the problem throughout adulthood.

### Aim

The aim of this study was to identify and synthesise evidence from qualitative primary studies on how AYAs in a non-clinical population experience living with persistent pain. A protocol describing the design of this study was published in the Joanna Briggs Institute Database of Systematic Reviews & Implementation Reports in 2014.<sup>32</sup>

### METHODS

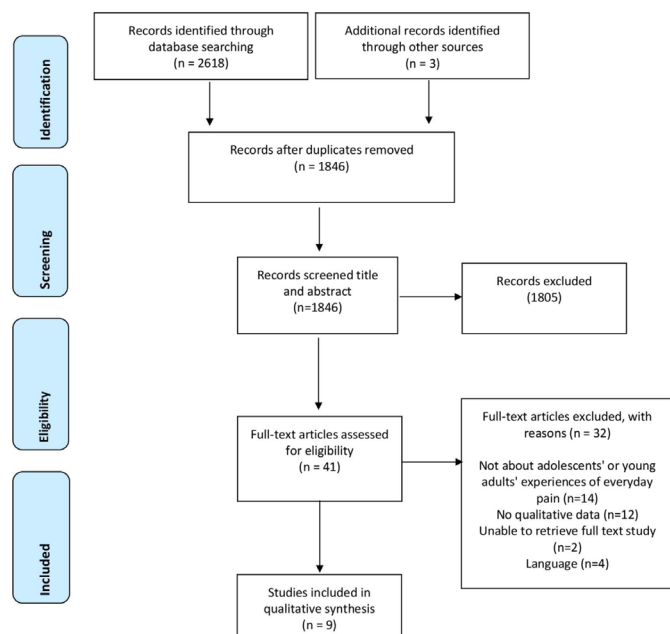
The metasynthesis was guided by Sandelowski and Barroso's guidelines for synthesising qualitative research from published qualitative primary research studies,<sup>33</sup> and based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for systematic reviews.<sup>34</sup> The metasynthesis process consisted of five steps: (1) formulating the purpose and rationale of the study; (2) searching for and retrieving relevant qualitative research reports; (3) critically appraising the included studies; (4) classifying the findings and (5) synthesising the findings.

### Search strategy

Our search strategy aimed to find both published and unpublished studies (Grey literature), and a four-step search strategy was developed by three of the authors (LF, KH and MSL). The electronic databases Medline (OVID), Embase (OVID), Cinahl (OVID), PsycINFO (OVID) and Proquest were searched initially in February 2017 using Medical Subject Heading and index term combinations of the keywords adolescents OR young adults AND pain AND qualitative studies. Second, after identifying relevant keywords (table 1), the search strategy was modified to fit each database in collaboration with a librarian, and the final search was conducted on 15 February 2021. Limiting age and language was the easy part; however, defining our search strategy concerning 'pain' was

**Table 1** Identified keywords used in the systematic literature search

Population	Phenomenon of interest	Context
adolescent* OR teenager* OR young adult* OR young people* OR young person* OR youngster* OR youth*	abdominal pain* OR back pain* OR backache* OR face pain* OR facial pain* OR headache* OR jaw pain* OR limb pain* OR low back pain* OR musculoskeletal pain* OR myofascial pain* OR neck pain* OR shoulder pain* OR tension headache* OR widespread pain* OR chronic pain* OR persistent pain* OR recurrent pain* OR everyday pain*	experience* OR comprehension* OR attitude* OR emotion* OR view* OR experience* OR opinion* OR perception* OR belie* OR feeling* OR know* OR understand* OR adaptation*



**Figure 1** The inclusion process.

challenging. Using the unspecific term ‘pain’ produced an overwhelming number of hits. Therefore, in collaboration with the librarian we decided to narrow the search to more specific types of pain described in previous relevant studies. The database search strategy with its search blocks is presented in [table 1](#).

The third step was to search the reference lists of the included studies, and finally the publications citing the included studies were checked for eligibility through the ‘find citing articles’ in OVID (PsycINFO, Nursing, Medline), ISI Web of Science, Scopus, Cinahl and Google Scholar. The flow diagram ([figure 1](#)) reflects all steps in the inclusion process.

### Inclusion criteria

This review aimed to consider studies published in English, Norwegian, Swedish or Danish describing a non-clinical population of adolescents (13–18 years) and young adults (19–24 years) with first-hand experiences of living with persistent pain not associated with cancer or similar life-threatening malignant diseases or clinical diagnosis, regardless of gender, ethnicity or country of origin, and length of years in living with everyday pain.

### Exclusion criteria

During the screening process, many studies focusing on specific non-clinical pain conditions were identified. According to the aim of this study, we consequently added the following exclusion criteria: pain in connection with medical procedures, cerebral palsy, sport activities, surgery, medication testing, treatment testing and instrument validation. Publications involving migraine headache or chronic tension-type headache were considered a clinical diagnosis and were therefore excluded.<sup>35 36</sup>

### Selecting and appraising studies for the metasynthesis

Four of the authors (LF, MSL, GR and KH) screened titles and abstracts and appraised relevant reports for inclusion according to the aim of the study and the inclusion/exclusion criteria. Any discrepancy between the researchers about whether a study should be included or not was discussed until consensus was reached. Of the 2618 records screened, nine were eligible for inclusion in the metasynthesis.

### Quality appraisal

The studies relevant for inclusion were independently critically appraised by two of the authors (LF and MSL) according to the Joanna Briggs Critical Appraisal Checklist for Interpretive and Critical Research.<sup>37</sup> Congruency between aims, methodology, data collection and analysis methods was evaluated. Overall, the congruency between philosophical perspectives, methodologies and methods used was strong. The exceptions were two studies with an unclear congruency between philosophical perspective and methodology.<sup>38 39</sup> The most poorly addressed issue was the influence of the researcher on the research and vice versa, and five of the nine studies included did not address this issue.<sup>38 40–43</sup> The results of the critical appraisal are presented in [table 2](#).

### Analysis

In line with Sandelowski and Barroso’s handbook, two approaches to qualitative research synthesis were used: qualitative metasummaries and qualitative metasyntheses.<sup>33</sup> Qualitative metasummaries are quantitative aggregations of qualitative findings from the included studies presented in [table 3](#). Qualitative metasyntheses are new interpretations of target findings from primary studies. The text from the results sections was considered the studies’ target findings consisting of quotations from AYAs, or the primary researchers’ interpretation of AYAs’ own experiences. The authors’ presentation of results from other studies, presentation of analytical procedures or discussion of findings were considered as non-target findings.<sup>33</sup>

After extraction, the target findings were imported into the data management software programme NVivo V.11 for further analysis.<sup>44</sup> A phenomenological–hermeneutic analysis inspired by Lindseth and Norberg<sup>45</sup> was performed by three of the reviewers (LF, BJ and KH). The text was initially read line-by-line to identify meaning units.<sup>46 47</sup> These were further condensed and abstracted to form main themes and subthemes. The authors discussed the analysis until consensus, and finally, a comprehensive understanding of AYAs’ experiences of living with persistent pain was described under three main themes.

### PATIENT AND PUBLIC INVOLVEMENT

This systematic review is based on published primary studies and does not involve public involvement.



**Table 2** Critical appraisal of the included studies

Criteria	Ahlgvist and Sällfors <sup>48</sup>	Hansen et al <sup>49</sup>	Hansen et al <sup>50</sup>	Hansen et al <sup>50</sup>	Hatchette et al <sup>30</sup>	Hatchette et al <sup>41</sup>	Henderson and Eccleston <sup>42</sup>	Henderson et al <sup>38</sup>	Huguet et al <sup>43</sup>	Kernick et al <sup>39</sup>	No/total
Y=yes											
n=no											
U=unclear											
NA=not applicable											
Congruity between philosophical perspective and research methodology?	Y	Y	Y	Y	Y	Y	Y	U	Y	U	7/9
Congruity between research methodology and research question or objectives?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
Congruity between the research methodology and the methods used to collect data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
Congruity between the research methodology and the representation and analysis of data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
Congruity between the research methodology and the interpretation of results?	Y	Y	Y	Y	Y	Y	U	Y	Y	Y	8/9
Researcher located culturally or theoretically?	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	8/9
Influence of the researcher on the research, and vice versa, addressed?	Y	Y	N	N	N	Y	N	N	N	Y	4/9
Participants, and their voices, represented adequately?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	6/9

Continued

**Table 2** Continued

Criteria	Ahlgvist and Sällfors <sup>48</sup>	Hansen et al <sup>49</sup>	Hansen et al <sup>50</sup>	Hatchette et al <sup>30</sup>	Hatchette et al <sup>41</sup>	Hatchette et al <sup>41</sup>	Henderson and Eccleston <sup>42</sup>	Henderson et al <sup>38</sup>	Huguet et al <sup>43</sup>	Kernick et al <sup>39</sup>	No/total
Y=yes	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
n=no											
U=unclear											
NA=not applicable											
Ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9
Conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9

## RESULTS

The findings are presented as metasummaries supported by tables and figures, and as a metasynthesis presented under three themes.

### Metasummaries

In five of the nine studies,<sup>30 38–43 48 49</sup> headache was the focused pain condition, and one study<sup>42</sup> included participants with various pain conditions in addition to headache. In the remaining three studies type of pain was not described.<sup>30 38 41</sup> Due to the low number of studies in the topic, we decided to include one study with participants aged in the lower age range (11–13 years).<sup>39</sup> All the studies were conducted in a Western cultural context, with three in Canada<sup>30 41 43</sup> and six in Europe (UK, Denmark and Sweden).<sup>38 39 42 48–50</sup> Eight of the studies had a specific focus on the pain management of AYAs, while one study focused only on their experiences of living with pain.<sup>39</sup> There was a preponderance of female participants (127/184). Characteristics of the included studies are presented in [table 3](#).

### Metasynthesis

Qualitative metasyntheses offer novel interpretations of the target findings from primary studies.<sup>33</sup> The three main themes characterising AYAs' experiences of living with everyday pain were: (1) juggling pain with everyday life; (2) exploring sources of information to manage everyday pain; (3) AYAs' use of medication to find relief and (4) non-pharmacological strategies for pain relief. These and related subthemes will be elaborated in the following text.

#### Main theme 1: juggling pain with everyday life

Five of the included studies provided data for this main theme.<sup>30 39 43 48 49</sup> Living with pain strongly influenced the participants' daily lives regarding education, social life and other activities.<sup>39 43 49</sup>

Education appeared to be demanding for AYAs and they were easily left behind and had to drop out of courses because of absence.<sup>43</sup> Pain related to stress was often connected to demanding situations in school such as examinations.<sup>49</sup> Participants also described how their teachers could be reluctant to accept the impact of headache on their school performance,<sup>30</sup> as expressed by one adolescent: 'Teachers think that you just want to get out of class.' Despite struggling for acknowledgement of their own pain, AYAs expressed negative attitudes towards peers' doubts that their pain expressions were real: 'Well the real pain is pain that everyone would feel. But 'wussy' pain is something that one person would whine about and the other person would just sort of live with it.'

Some of the participants had lived with their pain condition for a long time and were reluctant to believe that they could get rid of it: 'I've had them since I was so little I don't think there is much I can do.' Despite enduring pain, some of the participants even belittled the idea that their pain problem was serious enough to get

Table 3 Characteristics of the included studies

Author	Focus	Country	Type of pain	Recruitment	Sample and age	Design/method	Data collection/analysis
Ahlgvist and Sällfors <sup>48</sup>	Management of pain in daily life	Sweden	Low back pain	Previous participation in a physiotherapy intervention	6 males, 8 females Age 12–18 years	Grounded theory	Focus group interviews/classical grounded theory analysis
Hansen <i>et al</i> <sup>49</sup>	Use of medication	Denmark	Stress-related headache	Public high school	21 females Age 16–20 years	Phenomenology	Semistructured individual interview/phenomenological analysis
Hansen <i>et al</i> <sup>50</sup>	Norms for medicine use	Denmark	Headache or menstrual pain	Public high school	20 females Age 16–20 years	A qualitative approach inspired by phenomenology	Semistructured individual interviews/phenomenological analysis
Henderson and Eccleston <sup>42</sup>	Pain coping and associated Internet use	UK	Throat, abdomen, and head pain	Self-selected users of online health information in the last 6 months	5 females 3 males Age 12–17 years	Not described	Five online researcher-led discussions/Thematic analysis
Henderson <i>et al</i> <sup>38</sup>	Teenagers' use of the Internet for pain management	UK	Not available	Two schools: self-selected frequent Internet users but infrequent users of the Internet to seek out health or pain information	17 females 9 males	Not described	Semistructured focus groups/Thematic analysis
Kernick <i>et al</i> <sup>39</sup>	Experience of students with troublesome headache	UK	Headache	A large state secondary school	10 females 10 males Age 11–13 years	Consensual qualitative research	Semistructured interviews/Thematic analysis
Hatchette <i>et al</i> <sup>30</sup>	Maternal influences in adolescents' pain management	Canada	No exclusion variables	Junior high school	10 males (mean 13.6 years) 10 females (mean 13.4 years)	Grounded theory	Semistructured individual interview/constant comparative analysis
Hatchette <i>et al</i> <sup>41</sup>	The role of peer communication in socialisation of pain experiences	Canada	No exclusion variables	Junior high school	11 males age 12–15 years 13 females Age 12–15 years	Grounded theory	Focus group interviews/constant comparative analysis
Huguet <i>et al</i> <sup>43</sup>	Psychosocial support to headache sufferers using information and communication technology	Canada	Headache	Recruited through posters, brochures, online advertisements, letters and word of mouth	19 females 6 males Age 14–28 years (divided into three age groups)	A participatory design cycle	Two iterative cycles of three focus groups using a thematic survey guide/simple content analysis
Summary			School: 6 Other: 3	F: 127 M: 57 Total 184	GT: 3 Phenom: 2 Other: 2 NA: 2	Individual: 4 Focus group: 4 Online open discussion: 1	

NA, not available.

attention<sup>30</sup>: ‘Haven’t asked for help because headache is not serious, it’s just a headache.’

Ahlqwist and Sällfors<sup>48</sup> noted that the participants described how pain-free moments had a great impact on their coping and could put them more in control of their lives:

I changed my way of thinking and I am now more open with myself as well as with others. My mood has improved, and I feel that I want so much more than I did before. I have more energy and I understand myself better, and thinking in a different way even helps me to face other types of problems.

Their sleep quality and social life increased and they reached a turning point toward a more normalised life:

I got much better. And I think it was a real boost for me to feel that after the past twelve weeks I no longer had any pain. So, it was that easy. That was the end of it somehow. And since then I haven’t had any more problems with it. I feel I’m on a good path.

#### Main theme 2: exploring sources of information to manage everyday pain

Five of the included studies provided data for this main theme.<sup>38 39 42 43 48</sup> They revealed that AYAs living with enduring pain strived to gather information from different sources, hoping to find answers to their pain problems. AYAs’ information-seeking behaviour was influenced by the transition process from being a child to becoming an independent young adult; for some, their family’s norms strongly influenced their perceptions of pain and pain management.<sup>39 40</sup> The AYAs expressed a strong desire to be involved in their own pain management. They had a need to be informed about their pain condition and which relevant management strategies to use, in addition to social support.<sup>43</sup> The older the participants were, the more the family norms were substituted by perceptions of what was common, accepted, and expected by friends and peers.<sup>30 40</sup> They seemed to position themselves by attaining similar attitudes to the other group members: ‘They just take a painkiller, of course, like me, right. If they have a headache, they just take a painkiller.’

The AYAs expressed a strong desire to receive information about pain management, and information from professionals helping to strengthen their independence.<sup>39 43 48</sup> Besides having adults who told them what to do, the AYAs also experienced that being involved in finding solutions to their pain problems made them feel valued. The school health service staff played an important role in taking their pain seriously and in supporting them:

But I think that’s exactly what it was, a positive experience. That it was even available, that there was a place where you could go to see someone who was trained and could help you. And then to be able to agree on what the problem is and what to do about

it. And even in some way, it wasn’t just up to me, but like a joint effort. Yeah, and like someone who cared.

Seeking information through the media and the Internet appeared to be a way for AYAs to learn more about their pain condition, to be able to make informed decisions, and to handle their pain problems independently. The Internet was used intensively for checking symptoms before talking to others about them<sup>38 42 48</sup>:

I think it varies in what condition it is ... because, like say if it’s something that you don’t want anyone else to know about or something like that, then you’ll go and try and sort it out yourself [by using the Internet] rather than tell someone.

Information from the Internet was mainly used in addition to other information sources such as parents and professionals: ‘Mainly I would use the Internet as a source of supplementary information on top of any info that I get from my mum.’ AYAs also described how information on the Internet was experienced as unsuitable for their age or pain condition.<sup>38 48</sup> Others talked about anxiety and worries when they found information describing worst-case scenarios, and not information suitable for their condition:

I just had a cold or something and then it was like, are you having trouble breathing? And obviously I was, yeah, I’m congested so I do. And then straight away it was phone an ambulance, phone an ambulance when... and so it’s, it’s not detailed enough... And they have the whole list of things. At the start it’s just like ‘you’ve got a common cold’, and then at the end it’s like ‘you’re having a heartattack woooooo, spooky.

Comparing multiple Internet sources on the same subject was also used to validate information:

I would crosscheck any info which I would find with the info on other websites to see if it’s true. Also, I would look to see if the sites had cited any sources of info, as this usually suggests reliability.

The information on the Internet appeared to be less reliable than information from other sources, so the AYAs felt a need to validate it:

Because, like there are a lot of different things about, like on the Internet. Like some people just put like rubbish on the Internet but some people do actually like, like, know what they are talking about so it’s like really what you click on.

The severity and endurance of their pain problem seemed to determine whether they had to seek additional professional help:

I think, if it was a minor pain, you would just let it wear off, whereas if it were a major one you probably wouldn’t look online, you’d go and see your doctor or book an appointment with your doctor.



### Main theme 3: AYAs' use of medication to find relief

All of the nine included studies provided data for this main theme. AYAs' pain management was strongly influenced by their parents' or families' norms.<sup>38-41</sup> The younger the participants were, the more they followed the rules and guidelines provided by their parents.<sup>40</sup> The mothers were often in charge of the treatment of pain at home, and the use of OTC analgesics was common<sup>41</sup>:

But if it's, like, [paracetamol] and stuff like that, they've never been particularly against it. They've been really, like, 'if you feel unwell, better to take a couple of [paracetamol] than feel ill.

After acquiring autonomy concerning the use of analgesics, some of the AYAs described how they deviated from the many expectations of others despite receiving approval.

AYAs' threshold to take medication varied greatly.<sup>49</sup> Those who had low tolerance for pain had a similar low threshold for choosing analgesics to cope with pain.<sup>49</sup> While some regarded pain as a normal part of everyday life, others strongly avoided pain by using analgesics to relieve it: 'So I'm pretty good at taking an [acetaminophen] or [ibuprofen] or something, if (.) I mean, if I just have the teeny tiniest bit of a headache, because I hate having a headache.' Hansen *et al* focused on AYAs' motives for analgesic use, and noted that they were often grounded in a combination of performance and participation-related functions<sup>49</sup>:

And then just before, I thought, like, Oh no. This just cannot get spoiled... Now I'll take something and then I'll avoid getting a headache all day. If I just take five [acetaminophen] now, then nothing will come... It's just that if there was something I really wanted to do, then I was afraid there was something that would ruin it.

Performance was connected to being concentrated during school hours and managing homework in the evening; to do so, many participants used analgesics to keep up with both their own goals and their families' expectations:

I haven't taken medicine all my life. I think it was two years ago [starting high school], or something like that, where one really started. I mean if I, for example, had a headache, then I couldn't concentrate on my homework. And seeing as that's important, so that I can keep up in school, then one almost has to.

While many AYAs had increased their use of analgesics, others opposed this and demonstrated a different view:

...You don't take [paracetamol] at all? ... No, I try to avoid it. And they were really surprised, because I guess it's something they do, that's normal. And because it's normal, we don't talk about it. It's something one expects everyone does once in a while.

Umm. But then there's ones like me who don't do it so often."

Situations with low levels of stress were reported to reduce pain: 'If one is healthy in daily life, if one is less stressed and stuff like that, then it makes it so that one has less of a need for medicine.' In addition to reducing pain, some participants also used analgesics to deal with social anxiety, or to reduce the pressure in stressful situations:

I'm very good at it when I don't feel well, because I am so stressed every day and so then it's two [acetaminophen] or painkillers or something else that goes down fast, because I'm busy.

Even those who usually avoided taking pain medication regarded it as acceptable to do so to meet performance goals, and AYAs' expectations of being able to participate clearly influenced the use of analgesics.<sup>49</sup> At home, when they were in more relaxed surroundings, they often used alternative strategies to manage pain, such as taking a rest or going to sleep.<sup>49</sup> The availability of OTC medication influenced the use of analgesics: 'Because if you have a headache it's easier just to go to the Co-op and just go and buy paracetamol.'

Some of the participants talked about their friends' impulsive use of OTC medications:

Some people take too much medication. Some of my friends have (ibuprofen) and they just take it for everything. They don't wait and see if their headache goes away or wait and see if they're just overreacting or something. They just automatically take it.

Others were aware of the side effects of OTC medications and adjusted their use accordingly: 'When I feel like I'm getting a headache, I just take something... so then it's not going to get worse... I read the label to know the amount and how often to take them.'

Despite expressing concern about taking OTC analgesics, the participants also acknowledged the importance of using such medications if necessary: 'I'd rather have no pain for a little bit, than have to NOT take painkillers and have pain all the time.'

Non-pharmacological strategies for pain relief

In addition to analgesics, non-medical interventions were described as helpful tools to reduce pain.<sup>39 40 43 49</sup> Strategies providing AYAs with customisable and interactive coping tools, such as pain diaries, web-based information or tools to enable them to discuss their pain with peers, supported their ability to get a sense of control.<sup>43 48</sup> Trusting their body's ability to control pain rather than having the pain control their lives was described as increasing their self-efficacy<sup>48</sup>: 'I believe that my body can ... do many things. And I prove it too, I get rid of that headache every time, without taking anything.' Pain diaries were seen as useful tools to keep track of their pain and of factors that might be influencing it. Pain diaries could also support them in setting goals for themselves and in tracking their progress concerning pain and the



development of coping strategies. Non-medical interventions could be an attitude developed by the AYAs themselves, or as a part of the inherited family practice. The most common non-medical intervention for headache was to drink a lot of water, in addition to strategies such as sleeping, relaxing, getting fresh air, doing leisure activities, or taking vitamins.<sup>48 49</sup> Older AYAs tended to employ strategies such as using distractions, massage and exercise.<sup>43</sup> Younger AYAs trusted their mothers' recommendations, while older AYAs behaved more according to the more-or-less tacit norms within their peer group.<sup>40</sup> Alternative strategies to taking analgesics were discussed within their groups, and the participants reported how peers attempted to reduce their use of medication:

So it's often a debate. Because my friends are pretty observant about it. I've got a friend, T, who hates me for it. He can get so furious with me every time, 'Sit down and I'll make you some chamomile tea'... And then I say, 'No, T, I don't believe it works.' And then he goes crazy, because his opinion, he's 100% sure that natural medicine, it does the job just as well.

## DISCUSSION

This metasynthesis including data from nine qualitative studies with 184 participating AYAs (127 female and 57 male) aims to give a voice to those AYA who struggle with persistent pain. To cope with their pain, AYAs had to juggle pain with their everyday life, explore various sources of information to manage their pain, and use both pharmacological and non-pharmacological strategies for pain relief.

Our findings indicate how living with pain strongly influences AYAs' everyday life, and how their pain experience is influenced by culture, friends and family. Some of the AYAs experienced doubts that their pain expressions were real, and that persistent pain was regarded as just an excuse to avoid certain situations. The newly revised definition of pain from the IASP emphasises the emotional aspect of pain, and the importance of believing in the person having pain and claims that 'a person's report of an experience of pain should be respected.'<sup>51</sup> The IASP's<sup>51</sup> change from definition of pain as what a person says it is, to the definition of respecting a person's pain expression, could reflect our developing knowledge about the complexity of pain. This could be especially important in relation to AYAs with unspecific persistent pain.

The issue of not being believed could mirror a perception that today's young people may be less sturdy than previous generations,<sup>9 52</sup> despite research revealing increasing pressure on today's adolescents both physically, socially and emotionally.<sup>53</sup> Today's understanding of pain appears to be strongly influenced by defining it through its visible appearance, which undermines the complexity of enduring pain in a non-clinical adolescent population.

The AYAs experience of support from their school/college health service staff could indicate that they acknowledged their pain, even if it did not present as a somatic problem. Teachers play an important role in children's and adolescents' coping processes<sup>9 54</sup>; however, some of the AYAs in our study experienced teachers who did not believe them when they talked about their pain.<sup>39</sup> These findings are supported by studies showing that teachers tend to offer more support and empathy to an adolescent whose pain was related to a medical diagnosis than medically 'unexplained' pain.<sup>55 56</sup> Lack of understanding from teachers could be challenging, and be a part of the impaired education performance and high rates of school absenteeism described in research on AYAs with chronic pain.<sup>57</sup> It is important to acknowledge AYAs' experiences, as emphasised in the revised pain definition from the IASP: 'a person's report of an experience as pain should be respected.'<sup>51</sup>

Our findings indicate the extent of adolescents' search for answers from various sources to manage pain on their own. In a study from Australia, adolescents with pain were described to have little knowledge about pain and how to cope with it, and did not know who they could contact for help or information.<sup>55</sup> According to our findings, the internet was one of the most intensively used sources for exploring pain and pain management, although the information accessed was not always deemed suitable to provide the answers needed,<sup>58</sup> and AYAs sometimes found the information scary and inappropriate for their pain condition. These findings are in accordance with other studies that criticise information from the internet as not being individualised,<sup>54</sup> even if users' background is crucial in developing education programmes.<sup>59</sup> Another issue to consider is that much information posted on the internet is not evidence based. A study on pain and pain management revealed that few web-based applications were scientifically sound,<sup>60</sup> which could explain why information gleaned from the internet is often experienced as unsuitable, incorrect or exaggerated. The same question concerning reliability of information could apply to peers, who could have various reasons for sharing their opinions. Our findings show that it is important to be both equal to their peers, as well as to be able to oppose them. Both positions might strongly contribute to identity formation, and thus peers could be of great support to AYAs with pain.<sup>61</sup> Healthcare professionals seemed to be the people AYAs trusted the most, because of their knowledge about pain and ability to balance this with their previous experience of helping AYAs to manage their pain. These findings are supported by Fegran *et al*<sup>62</sup> who describe AYAs experiences of healthcare professionals' crucial role in caring for children and adolescents with chronic conditions during the transition to adolescence and adult life.

Some of the participants in our review expressed concerns about taking OTC analgesics to reduce stress and anxiety. However, they also acknowledged the importance of using medications if necessary. Pain management appeared to be strongly influenced by their parents'



or families' norms, even if family attitudes as a source for managing pain gradually weakened as AYAs matured. These findings are in accordance with other studies showing that adolescents' primary source of information for using OTC analgesics is their parents, and that the mother's attitude toward using OTC analgesics influenced adolescent use.<sup>28 41 63</sup> The increasing use of OTC drugs is worrying because continuous use might prevent adolescents from learning healthier coping strategies. Instead of helping the adolescents to cope with pain, high-frequency use of OTC drugs could develop to become the start of lifelong use of medication.<sup>29</sup>

### Clinical implications

Our findings might help increase healthcare professionals' knowledge of how to approach and support AYAs with enduring everyday pain. Public health nurses and school nurses should acknowledge their crucial roles in respecting AYAs' pain expressions and support them to use healthy coping strategies. Because of the increase in the use of OTC medications, they also have a role in informing AYAs about the side effects of such agents.

### Strengths and limitations

The transparent and systematic methodological approach of this metasynthesis is a strength. One limitation could be the exclusion of studies not concerning everyday pain. On the other hand, this limitation is a strength as these AYAs' voices are seldom heard compared with those recruited from a clinical context. Synthesising data from nine qualitative studies with 184 participants provided rich qualitative data and in-depth knowledge about these AYAs' experiences. It could be a limitation that five of the nine studies focused on headache. On the other hand, it provides an important elaboration of previous quantitative studies describing headache as one of the most common pain conditions in adolescents.<sup>12</sup> Another limitation is that all the studies were conducted in Western cultures. Studies from other contexts, or studies of exposed populations—for instance refugee AYAs—clearly would have helped to broaden the picture.

### CONCLUSION

These AYAs experience of how pain influences everyday life, and their striving to find relief from pain by support from family, friends, professionals and the internet should be strongly respected. Public health nurses and other healthcare professionals encountering AYAs need to respect their pain experiences, and to support them in healthy coping strategies. Further studies on this issue are needed, especially research focusing on AYAs pain in exposed populations and AYAs from non-Western cultures.

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**Acknowledgements** Librarian Ellen Sejersted at the University of Agder assisted in the development of the search strategy.

**Collaborators** Librarian Ellen Sejersted at the University of Agder contributed to the systematic literature search.

**Contributors** LF, MSL and KH designed the research project and developed the research plan. Librarian Ellen Sejersted at the University of Agder, LF, MSL and KH were responsible for the literature search, and LF, MSL, BJ and KH were responsible for the analysis. LF, MSL, BJ, TW, MH, ÅS, GR, SH and KH were involved in the screening and inclusion of studies, reviewed the manuscript, and contributed to the revision of the paper. All authors read and approved the final version of the paper.

**Funding** The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available on reasonable request.

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