Adolescents and young adults' experiences of living with everyday pain: a systematic review protocol of qualitative evidence

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Review question/objective

What are the experiences of adolescents and young adults (AYA) living with everyday pain?

The objective of this systematic review is to identify and synthesize the best available evidence from qualitative primary studies on how adolescents and young adults' experience living with everyday pain.

Background

During the last 10 years pain has been recognized as a growing health problem in children and adolescents worldwide, and there is increasing evidence that daily life, function and well-being are affected by pain.[1] The literature shows that as much as 15%-30 % of adolescents are suffering from persistent or chronic pain conditions, and this is regarded as a significant public health problem.[2-6]

According to the International Association for the Study of Pain (IASP), pain is always subjective.[8] Pain is a common concept in the nursing literature, and McCaffery's well-known definition of pain is often cited: "Pain is whatever the experiencing person says it is, existing whenever he says it does".[7(p.15)] The International Association for the Study of Pain also recognizes the central role of emotions in pain defining pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage".[8(p.94)] According to Eccleston two core aspects of pain are however missing from these definitions. In addition to the private felt character of pain it is also a social

and communicative event. Pain expression may function to communicate to others the possibility of danger and presence of personal suffering.[9] Further pain may function to override other concerns and to motivate escape or avoidance. *Everyday pain* is described by Eccleston as: "pain that is clinically unimportant that arises from normal everyday activity. Pain functions to interrupt current concerns and promote problem solving typically in the form of escape, pain management, or request for assistance".[10] (p.47)

The literature shows that self-reported pain increases with age, and older children report more pain than younger children.[3,5] The expression of pain as having an emotional basis also increases with age, and is expressed more frequently by adolescents.[11] The most commonly reported pains in adolescents are headache, abdominal pain, backache, and limb pain, and many adolescents report multiple pain sites.[5] Qualitative studies on adolescents' experiences reveal how living with chronic everyday pain strongly influences adolescents' daily life in different ways. It may result in absence from school, poor school performance, problems with social activities, isolation, stigma and sleeping problems.[3,12-14]

The adolescents' pain experience is influenced by a complex interaction between biological, sociocultural, and psychological factors.[15] Children from families with low socioeconomic status report more pain than children from families with higher socioeconomic status.[6,16] Moreover social factors such as parents' income, education, and also psychosocial variables, such as divorce, anxiety, and depression, have been shown to be related to pain in children and adults.[16] Pain may be symptoms of underlying causes, and have been associated with psychosomatic problems, such as stress, problems in relations with schoolmates, and with lack of sleep or exercise.[17] The association between stress and headaches is stronger among teens with frequent headaches,[18] and living with a high stress level over time may give adolescents feelings of helplessness.

It has been suggested that changes in modern society and in the lifestyles of adolescents such as their frequent use of computers, more sedentary behaviour, greater stress, less sleep and greater psychological burdens may contribute to the increase in self-reported pain.[19,20] Managing stability through stressful challenges called allostasis (stability through change) is a challenge to adolescents and young adults.[21] Continuous stress may induce allostatic overload, which might partly explain why some adolescents frequently experience pain and become high frequency users of over-the-counter (OTC) analgesics.[22] Holmström's study of Swedish teenagers' OTC drug use revealed how vulnerable teenagers may be as new consumers of OCT drugs. [23] A knowledge gaps among the teenagers concerning OTC drugs was identified, and also that their OCT drug use was significantly influenced by parents and peers.

The high prevalence of pain is a cause of concern, especially because pain negatively affects adolescents' daily life and activities in different ways. Adolescence is a period in life in which great changes occur, and children are faced with physical, psychological and social changes that may be challenging. Pain problems may also have serious long term consequences, as pain problems can persist into adulthood and develop into chronic or persistent pain.[24] Studies show that children with recurrent headaches, abdominal pain and other symptoms are at increased risk of developing chronic musculoskeletal pain in adulthood.[25]

Different coping strategies are described in the literature, and a passive coping strategy has been associated with higher levels of pain. [26] Peer influence is apparent in the socialization of pain experience, [27] and qualitative studies have shown that girls are more likely to talk to friends about pain problems than

boys. [28] Studies have also showed that more girls than boys use pain medication as coping strategy. [28] Moreover, qualitative studies illuminated that children describe a stressful life and too little sleep as common causes of pain.

Adolescents' and young adults' search for pain relief may lead to an increase in the use of pain relievers as OTC analgesics, illicit drugs and alcohol.[29] Recent Nordic studies show that adolescents have a high frequency use of analgesics.[22] The frequence of adolescent users of OTC analgesics in Norway and Denmark has also increased remarkably from 5% among boys and 14% among girls, to 26% for both genders during the last years.[22,23,30]

Even if we have knowledge of the prevalence and impact of pain, and this topic has been well investigated during the last years, much remains unknown about the causes of pain, adolescents own experience of living with pain, and also their coping strategies. To be able to support adolescents to relate to their pain in such way that it does not lead to chronic or persistent pain, we need more knowledge about their own thoughts and experience according to pain experience. There are few such studies in a non-clinical population.[9]

An initial search on the keywords "adolescent*" OR "young adults" AND "pain" in the databases Medline, CINAHL, PsychINFO, EMBASE, JBIConnect+, PROSPERO or Cochrane Library indicated that no systematic review of qualitative evidence on this topic exists, or is currently underway. Thus a qualitative systematic review with metasynthesis by meta-aggregation may provide important and relevant evidence about this topic.

Keywords

adolescent; everyday pain; pain; young adult; qualitative

Inclusion criteria

Types of participants

This review will consider studies that include adolescents of ages 13-17 years, and young adults of ages 18-24 years (AYA), who have first-hand experience of living with everyday pain regardless of gender, ethnicity or country of origin, and length of years in living with everyday pain.

Phenomena of interest

Adolescents and young adults' own descriptions of experiences of living with everyday pain.

Everyday pain is defined as persistent, recurrent or episodic pain in any body site, not associated with cancer or similar life threatening malignant disease

Context

Adolescence and young adulthood.

Types of studies

This review will consider studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research. In the absence of research studies, other texts such as opinion papers and reports will be considered.

Studies focusing on the following issues will be excluded: pain associated with cancer or similar life threatening malignant disease, procedure pain or pain in connection with surgery, pain associated with medical procedure, medication testing, treatment testing or instrument testing, or pain associated with sport activities.

Search strategy

The search strategy aims to find both published and unpublished studies. A four-step search strategy will be utilized in this review. An initial limited search of Medline and CINAHL has been undertaken and was followed by analysis of the text words contained in the title and abstract and of the index terms used to describe the articles. The following initial keywords Adolescent, Teenager and Pain were used to identify a number of keywords (Table 1).

Table 1: Identified keywords and index terms

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

Secondly a systematic search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles will be searched for additional studies. Finally all identified research reports will be subject to forward citation searches to reach as complete as possible inclusion of studies in the review.

Studies published in English, German, Danish, Swedish and Norwegian will be considered for inclusion.

Due to the increasing number of studies on AYA's pain during the last decade only studies published between 2005 and November 2014 will be considered for inclusion in this review. The databases to be searched include:

PubMed

CINAHL

PsycINFO

EMBASE

Grey literature is a core component in a systematic review. In the context of this review grey literature such as theses and dissertations will be considered for inclusion because they presumably report findings relevant for this review. The search for unpublished studies will include:

Google Scholar

Mednar

ProQuest Dissertations and Theses

Journals publishing in Danish, Swedish and Norwegian relevant for this systematic review are all indexed in the above mentioned databases.

Systematic searches will be developed for each database and conducted in cooperation with a research librarian.

Assessment of methodological quality

Qualitative papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). In the absence of qualitative research studies, the authenticity of opinion papers will be assessed using the Joanna Briggs Institute Narrative, Opinion, and Text Assessment and Review Instrument (JBI-NOTARI). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. Authors of primary studies will be contacted for missing information if needed.

Data collection

Data will be extracted from individual studies independently using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data synthesis

Qualitative research findings will, where possible, be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings (Level 1 findings) rated according to their quality and categorizing these findings on the basis of similarity in meaning (Level 2 findings). These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (Level 3 Findings) that can be used as a basis for evidence-based practice. Where textual pooling is not possible, the findings will be presented in narrative form. In the absence of qualitative research studies, textual papers

will, where possible, be pooled using JBI-NOTARI. This will involve the aggregation or synthesis of conclusions into categories, which are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings (through a similar process to that stated above for JBI-QARI). Where textual pooling is not possible, the conclusions will be presented in narrative form.

Conflicts of interest

None

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Appendix I: Appraisal instruments

QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

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Appendix II: Data extraction instruments

QARI data extraction instrument

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐