Behavioral pain indicators for adults with an intellectual disability: a scoping review protocol

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ABSTRACT

Objective: This scoping review aims to identify and map the behavioral pain indicators observed when adults with an intellectual disability experience pain.

Introduction: Adults with an intellectual disability have more health problems than the general population. The likelihood that this population will experience pain is high, but intellectual disability can obstruct the verbal expression of pain. Adults with an intellectual disability express pain via behavioral pain indicators; however, because no behavioral pain scale exists for this population, observers may misinterpret the pain experienced by adults with an intellectual disability.

Inclusion criteria: The review will examine literature about behavioral pain indicators for adults with any type of intellectual disability who are suffering from any type of pain in any country or care setting.

Methods: The review will be conducted according to the JBI recommendations for scoping reviews. A preliminary search focusing on the concepts of intellectual disability and pain measurement was conducted for PubMed and CINAHL in March 2022. Once the protocol is validated, searches will also be carried out in Embase, JBI EBP Database, the Cochrane Database of Systematic Reviews, ProQuest Dissertations and Theses, PsycINFO, Web of Science Core Collection, ERIC, Google Scholar, MedNar, and the websites of relevant professional associations. Titles and abstracts, and then full-text studies, will be selected independently by 2 researchers and assessed against the inclusion criteria. Relevant information will be imported into a data chart. Any behavioral pain indicators identified will be classified into 14 behavioral categories.

Review registration number: Open Science Framework osf.io/8xckf

Keywords: behavior; intellectual disability; learning disability; pain indicators; pain measurement

JBI Evid Synth 2023; 21(1):254–263.

Introduction

Intellectual disability (ID) is characterized by significant limitations in intellectual functioning and adaptive abilities (conceptual, social, and functional skills), and appears during a child's developmental period.[1] ID affects 1% to 2% of the world's population[1,2] and can be classified into 4 categories: mild, moderate, severe, and profound. The more profound the degree of ID, the less the person is able to communicate verbally.[1]

Pain can be defined as "a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components."[3(p.28)] This definition of pain was adopted for this review because prior definitions fail to consider the cognitive and social components of pain.[3] This definition will enable us to use a broader concept of the expression of pain for adults with ID.

Adults with ID experience pain no differently to the rest of the population.[4,5] Indeed, recent studies have suggested that adults with ID are more sensitive to pain.[6,7] When exposed to a painful stimulus, they have a longer reaction time but a higher reaction intensity than the general population.[6,7] The literature also shows that adults with ID have more numerous physical[8,9] and mental[8] health problems than the general population, even though their health problems are often under-diagnosed. Adults with ID are also more frequently in need of care than the general population.[1,9] The likelihood that an adult with ID will experience pain is therefore high. Indeed, the prevalence of chronic pain in this population is between 14% and 76%.[8,10] Other studies confirm that the prevalence of chronic pain among adults with ID is significantly higher than in the general population.[6,11]

The limited adaptive abilities resulting from ID can obstruct or inhibit verbal expressions of pain and, thus, self-reporting.[4,12,13] Adults with ID express their pain via behavioral pain indicators.[12] These indicators are defined by the social communication model of pain used in many international pain studies; they are observable, spontaneous reflexes and reactions caused by pain,[3] such as changes in facial expressions or motor activities.[12] Evidence-based practice guidelines recommend the use of a behavioral pain scale for people who cannot communicate verbally.[5] Currently, no validated, reliable behavioral pain scale exists for recognizing and assessing pain in this vulnerable population.[14]

In the absence of any validated, reliable pain scale for adults with ID, observers may misinterpret their behaviors.[13] Family caregivers and social services carers often have expert knowledge about the person and their situation. Their role includes providing day-to-day care,[15,16] advocacy,[16] and assistance with communication, including speaking on behalf of adults with ID.[17] Although they are also often able to determine whether the adult with ID is in pain,[15,18] they often underestimate the intensity of that pain.[5,19] Health care professionals who do not take care of adults with ID on a daily basis may have difficulty assessing pain in this population.[18,20] Difficulties in recognizing pain and its behavioral indicators means that the pain experienced by adults with ID is under-evaluated and under-treated.[3,4]

A preliminary search was conducted in March 2022 in the CINAHL (EBSCO) and PubMed databases. We found no existing or in-progress scoping reviews on behavioral pain indicators for adults with ID. We only identified 1 systematic review conducted by de Knegt and colleagues[12] in 2013, who aimed to identify behavioral pain indicators in people with ID. The review included studies that incorporated both children and adults with ID; however, the literature has shown that behavioral pain scales considered valid and reliable for children with ID are not applicable to adults with ID.[14] This systematic review did not include expert reports[12]; however, the preliminary literature search conducted for our planned scoping review identified several expert reports dealing with this topic.[21-24] It also highlighted that about 62% of the articles identified in PubMed and 57% of those identified in CINAHL were published after 2013; therefore, interest in this topic is growing. Our preliminary analysis demonstrated that new behavioral pain indicators have been identified for adults with ID[7,25-29] since de Knegt and colleagues' 2013 literature review.[12] These include using specific sounds, vocalizations, or movements to indicate pain,[23,26] or a change in interest in one's environment.[21] These behavioral pain indicators can nevertheless be classified within the categories of behavior developed by de Knegt and colleagues.[12] The literature we have presented here is not exhaustive but demonstrates new knowledge warranting further investigation.

The planned scoping review aims to identify and map the behavioral pain indicators observed when adults with ID experience pain. This mapping exercise will then be used to develop a behavioral pain scale for this population. Ultimately, this scale should enable family caregivers, social services carers, and health care professionals to better assess the pain experienced by adults with ID. They should then be able to treat that pain more effectively and thus reduce the health inequalities experienced by adults with ID.[1]

Review question

What behavioral pain indicators have been identified in the literature for adults with ID experiencing pain?

Inclusion criteria
Participants
The planned scoping review will consider any scientific literature concerning adults with any diagnosis of ID. Many different English terms can be used

to describe ID. Articles referring to ID, developmental disabilities, intellectual impairments, mental deficiencies, mentally disabled persons, mental retardation, developmental disorders, or learning disabilities will be included.

Furthermore, to collect all the behavioral indicators observed when adults with ID experience pain, articles addressing any degree of intellectual impairment will also be included. Studies will be included even if the degree of ID is not defined. Studies including different categories of non-verbal patients (non-verbal patients as a result of ID; non-verbal patients as a result of unrelated, non-ID reasons) will also be included if they differentiate between those categories in their results.

Studies that include both adults and children with ID in their sample will be included in our review in order to capture the most representative map of behavioral pain indicators. However, studies with samples that only include children with ID will be excluded because the literature suggests that valid, reliable pain scales for children are neither valid nor reliable for adults with ID[14,30] or for the general population.[5]

Concept
Literature dealing with behavioral pain indicators of acute, chronic, procedural, or induced pain will be considered. Articles will be included even if the type of pain is not specified. Articles on the development of behavioral pain scales for adults with ID may also be included.

The scoping review will focus on behavioral pain indicators of all kinds. Literature dealing with motor activities, facial activities, social-emotional indicators, physiological indicators, verbal expressions, non-verbal vocal expressions, self- or hetero-aggressive behaviors, agitation, activities of daily living, exacerbation of the usual symptoms caused by ID, and stereotypical movements related to expressing pain among adults with ID will all be included.[12] If other categories of behavior are identified during analysis, the literature addressing them will be included as well.

Studies have used different methods to identify pain-related behaviors among adults with ID: observation; asking the adult with ID directly; and reports from family caregivers, social services carers, and/or health care professionals. Behavioral pain indicators described in the literature by adults with ID or by their family members, social carers, and health care professionals will also be taken into consideration. Literature involving health care professionals will be taken into account irrespective of whether they are specialized in caring for this population. Indeed, in order to obtain the most exhaustive list of behavioral pain indicators possible, we have formulated no specific exclusion criteria.

Context
Literature from any contextual setting will be included. Publications from any geographical or cultural location will be included.

Types of sources
This review will consider all primary studies, including qualitative, quantitative, or mixed methods designs. Reviews, experts' reports, opinion articles, gray literature, and clinical guidelines dealing with the topic investigated will also be included. Conference abstracts will be excluded from the review as they usually provide limited data.

Methods

The planned scoping review will be conducted in accordance with the JBI methodology for scoping reviews.[31] The review title has been registered in Open Science Framework (osf.io/8xckf).

Search strategy
A 3-step search strategy will aim to find both published and unpublished literature. A preliminary search equation focusing on the concepts of ID and pain measurement was generated for the PubMed and CINAHL (EBSCO) databases in March 2022. The terms used in the titles and abstracts of articles related to our research question, together with the index terms linked to those articles, were used to develop a full search strategy (see Appendix I). For pain, we selected the descriptors of pain and pain measurement. For ID, we selected the descriptors of ID, developmental disabilities, persons with mental disabilities, child development disorders, pervasive and learning disabilities, and complications. All these descriptors were also used as keywords for our preliminary search for titles and abstracts. The following keywords were added for ID: mental retardation, mental infirmity, mental handicap, mental impairment, development disability, developmental retardation, development

retardation, Down syndrome, fragile X syndrome, Rett syndrome, Prader–Willi syndrome, trisomy 13, trisomy 21, Williams syndrome, disintegrative disorder, mentally disabled, intellectual impairment, and mental deficiency.

Following this initial analysis, a research equation was generated for the PubMed and CINAHL (EBSCO) databases in consultation with a librarian. The tests carried out revealed that using the descriptor of "pain" created a lot of search noise. A second analysis revealed that the term "pain" was always associated with other terms. The keyword "pain" was therefore associated with assess, measure, scale, index, questionnaire, behavior, observation, cues, recognition, and identification. After this exercise, as recommended by JBI,[32] the research equation was reviewed and validated by a second librarian.

The search strategy was designed to filter out articles published before 2000 because the earliest studies confirming the ability of adults with ID to feel pain were published in that year. Only studies written in English, French, German, Italian, Portuguese, and Spanish will be included because these are the languages spoken by the research team.

Once the protocol has been validated, searches will be conducted in the following databases: PubMed, CINAHL (EBSCO), Embase, JBI EBP Database (Ovid), Cochrane Database of Systematic Reviews, ProQuest Dissertations and Theses, PsycINFO (Ovid), Web of Science Core Collection, and ERIC (Ovid). To identify gray literature, a search will be conducted through Google Scholar, MedNar, and the websites of relevant professional associations, for example, the International Association for the Study of Pain, the American Association for Intellectual Disability, and the American Nursing Pain Management Association. Websites of other significant associations identified when screening selected articles will also be searched. The reference lists of articles to be included in the scoping review will also be checked by 2 reviewers to identify literature dealing with the topic under study.

Study selection
All citation results will be uploaded to EndNote v.20 (Clarivate Analytics, PA, USA), and duplicates will be removed. Titles and abstracts will be screened independently by 2 reviewers using Covidence (Veritas Health Innovation, Melbourne, Australia) to ensure they meet our inclusion criteria. At this stage, a pilot

test based on 50 articles will be done. During the screening, the 2 reviewers will also examine the index terms used to describe the articles selected for the second stage of analysis. If this first analysis of the articles reveals other relevant keywords or descriptors, these will be added to the search equation. If new, relevant references are revealed, they will be added to the EndNote and Covidence files. Any changes will be described in the final report.

The 2 reviewers will then carry out a full-text examination of the selected articles following a similar process. The results of these searches will be described in a PRISMA flow diagram.[33] The reviewers will document the reasons for the final inclusion or exclusion of each full text in their report. This first analysis, based on 50 articles, will enable the reviewers to build a common understanding of the inclusion criteria. If the pilot testing of source selectors shows a degree of reviewer agreement greater than or equal to 75%, they will analyze all the references as described above. If the pilot shows a degree of reviewer agreement of less than 75%, a second pilot test of source selectors will be carried out with 50 new references.

The 2 reviewers will compare and discuss their results throughout the process. If they cannot resolve any disagreements through discussion, a third reviewer will be asked to make a decision.

Data extraction
The characteristics of the included articles will be imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI; JBI, Adelaide, Australia).[34] All relevant information will be imported into a data charting form adapted from the standardized JBI draft data extraction form (see Appendix II). The data charting form will include information on the citation details (author[s], title, year of publication, and journal), country of origin (where the source study was conducted), context (type of setting where the study was conducted), objective(s), design, population, and sample size (number of participants, age, sex, ID diagnosis, level of ID), respondents (adult with ID, health professional, family caregivers, or social services carers), pain description (type, intensity, and location), methods (outcomes and details of these, or description of the intervention), key findings related to the scoping review question, and limitations. In the key findings section, the 2

reviewers will note all the behavioral pain indicators observed when adults with ID experience pain. No statistical results will be reported.

The 2 reviewers will independently pilot test the data charting based on the first 5 articles selected. The results of this data extraction will be compared and discussed, and any disagreements will be resolved by a third reviewer.

In order to respect the iterative process of the scoping review, any sections added to the data charting form will also be discussed by the 2 reviewers at the end of the pilot testing. Any changes made to the data extraction process will be described in the final report.

Data analysis and presentation

Behavioral pain indicators will be classified using the categories developed for the systematic review by de Knegt and colleagues.[12] These categories are motor activities, facial activities, social-emotional indicators, physiological indicators, verbal expressions, non-verbal vocal expressions, self- or hetero-aggressive behaviors, agitation, activities of daily living, exacerbation of usual symptoms caused by ID, and stereotypical movements (see Appendix III).[12] The 2 reviewers will independently pilot test the data classification using the first 5 articles selected. To do this, once the data charting of the selected articles has been finalized, the 2 reviewers will independently classify the behavioral pain indicators into one of the identified categories. If behavioral pain indicators cannot be classified into the categories identified by de Knegt and colleagues,[12] the reviewers will discuss whether new behavioral categories need to be developed. If pilot testing shows that the 2 reviewers cannot agree on the classification of the data or if new behavioral categories are introduced, a new pilot testing will be carried out on another 5 articles that have passed the source selection process.

At the end of pilot testing, the 2 reviewers will continue to independently classify the behavioral pain indicators into their behavioral categories. The reviewers will be free to discuss the addition of behavioral categories at any point in this process. If changes are made, they will be mentioned in the report.

The 2 reviewers' results will be compared and discussed continuously throughout the process. If, after discussion, disagreements persist, they will be resolved by a third reviewer.

The results section will include: study characteristics, the different populations examined, the types of pain addressed, the contexts examined, and a mapping of the behavioral pain indicators observed among adults with ID. The selected articles will be presented in a table containing the following sections: authors, design, objectives, sample, types of pain, main results, limitations, and references (see Appendix III). The section on behavioral pain indicators will also include a table containing the following sections: pain behavior categories, behavioral pain indicators, and references (see Appendix IV). A narrative summary will accompany the charted results, describing how the results relate to the scoping review's objective and research question.

Funding

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Appendix I: Search strategy

PubMed
Search conducted on March 28, 2022

("Pain Measurement"[Mesh] OR (pain[tiab] AND (assess∗[tiab] OR measur∗[tiab] OR scale∗[tiab] OR index[tiab] OR questionnaire∗[tiab] OR behavior∗[tiab] OR behaviour∗[tiab] OR observation∗[tiab] OR cues[tiab] OR recogni∗[tiab] OR identif∗[tiab])))

AND

("Intellectual Disability"[MeSH] OR "Developmental Disabilities"[MeSH] OR "Persons with Mental Disabilities"[MeSH] OR "Child Development Disorders, Pervasive"[MeSH:NoExp] OR "Learning Disabilities/complications"[MeSH:NoExp] OR "intellectual disabilit∗"[tiab] OR "mental disabilit∗"[tiab] OR "mental retardation"[tiab] OR "mental infirmit∗"[tiab] OR "mental handic∗"[tiab] OR "mental impairment∗"[tiab] OR "developmental disabilit∗"[tiab] OR "development disabilit∗"[tiab] OR "developmental retardation∗"[tiab] OR "development retardation∗"[tiab] OR "down syndrome"[tiab] OR "fragile x"[tiab] OR "Rett "[tiab] OR "Prader Willi"[tiab] OR "Trisomy 13"[tiab] OR "trisomy 21"[tiab] OR "Williams Syndrome"[tiab] OR "Mentally Disabled"[tiab] OR "intellectual impairment∗"[tiab] OR "mental deficienc∗"[tiab] OR "developmental disorder∗"[tiab] OR "development disorder∗"[tiab] OR "disintegrative disorder∗"[tiab])

PubMed result: 888 results with the limitation of no articles published before 2000.

Appendix II: Draft data extraction form

Citation details: author(s) year of publication, title, journal, and country	Design and objectives	Context and methods	Population and sample	Types of pain	Main results	Limitations	Ref

Appendix III: Table presenting the selected studies

Authors	Design	Objective	Sample	Type of pain	Main results	Limitations	Ref

Appendix IV: Behavioral pain indicators observed in adults with intellectual disability

Pain behavior categories	Pain indicators	References