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A Scoping Review Protocol to Map the Evidence of Experiences Related to Adolescent Idiopathic Scoliosis

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ABSTRACT

Introduction Adolescent idiopathic scoliosis, the diagnosis and management of this condition, may lead to poorer body image and diminished psychosocial functioning. Furthermore, treatment, especially bracing and surgery as well as screening, remain controversial and debated, with an unclear evidence-base. Personal experiences in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as highly valued. Nonetheless, people's experiences related to adolescent idiopathic scoliosis is an issue underrepresented in current systematic reviews and systematically developed recommendations. There appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications in this field. The objective of this planned scoping review is to explore and map the available evidence from various sources to address a broad question of what is known about experiences of all those touched, directly and indirectly, by the problem of adolescent idiopathic scoliosis.

Methods and analysis We based our protocol on the Joanna Briggs Institute's scoping review method, including the Population – Concept – Context framework, to formulate the objectives, research questions, eligibility criteria, and conduct characteristics of the study. We will consider any primary study designs, research synthesis reports, as well as narrative reviews and opinion pieces. We will not restrict eligible publications to English language. Search and selection processes will include academic and grey literature searches using multiple electronic databases, search engines and websites, hand searches, and contacting the authors. We will use a customised data charting table and present a narrative synthesis of the results.

Ethics and dissemination Scoping review is a secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval. We will submit the report to a peer-reviewed journal and disseminate it among professionals involved in scoliosis management, guideline and recommendation development, and policymaking.

ARTICLE SUMMARY

Strengths and limitations of this study

- This article outlines a protocol of the first research synthesis study focusing on people's experiences related to adolescent idiopathic scoliosis, an issue underrepresented in current systematic reviews and systematically developed recommendations in this field.
- The scoping review characteristics, multiple database and hand searches for academic and grey literature, will increase the likelihood of thorough mapping of the evidence concerning this person-centred subject matter.
- Due to the variety of the potentially included study designs we will not conduct a critical appraisal of the methodological quality or risk-of-bias analyses of the included sources of evidence.
- For methodological and practical reasons, we will not consider sources from social networks and blogs, which is a potential limitation, giving the subject matter of our study.

INTRODUCTION

Adolescent idiopathic scoliosis (AIS) is a complex health condition that is defined as a lateral spine curvature of 10º or more, of an unknown origin, that manifests in children older than ten years of age [1-3]. Mild AIS is present in about 1.5 – 3% of adolescents, while more severe curves exceeding 40º are found in 0.04 – 0.3 %. The female to male ratio ranges from about 1.4:1 for curves of less than 20° to 7.2:1 for curves exceeding 40° [4].

This structural deformity of the spine and trunk, depending on its severity, may lead to pain and pulmonary or cardiac complications [1-4]. On the other hand, this health condition, but potentially also the diagnosis and treatment, may be associated with lower self-esteem and poorer body image, as well as worse psychosocial functioning [1, 5-7]. All these may also touch significant others [8, 9]. Treatment of AIS, especially bracing and surgery, are controversial as regards side effects and harms [1, 5, 6, 10-12]. Routine screening for scoliosis is also debated, with conflicting recommendations [13-15]. The evidence-base for both screening and treatment is very unclear [11, 12, 14, 16].

Based on recent comprehensive systematic reviews [11, 12], impactful narrative reviews [1-3], and tertiary evidence synthesis studies [14, 16], little is considered and understood about what the people diagnosed with, and treated for, AIS, their significant others, and other people, experience about this condition. Furthermore, there appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications [12, 14, 16]. It is especially significant as this health problem emerges in a fragile time of puberty and adolescence and as ethical doubts have been raised concerning management of AIS [6, 11, 15]. The recommendations for research and management of AIS [17-20] seem to uphold this state of affairs.

This is striking in the Evidence-Based Practice perspective, since recommendation formulation principles have evolved in recent years [21-23]. Experiences of people, in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as principal and highly valued [24-26]. The Evidence-Based Practice triad addresses expertise of professionals, evidence for effectiveness and safety of interventions, but also a person's perspectives, with their opinions, attitudes, values, and views [27, 28]. Those perspectives are also important in terms of the acceptance of treatment, an issue discussed in scoliosis management as being crucial and problematic [1, 6, 16]. More generally, personal factors concerning illness as a perceived, personal experience, in contrast to disease as a medical term [23, 25, 28, 29], are vital as regards management of AIS. A better understanding of these aspects needs to be opened with mapping of evidence.

Why scoping review. To the best of our knowledge, research syntheses addressing various aspects of AIS, typically apply the standard method of systematic review of intervention studies, and are based exclusively on the evidence from controlled trials and quantitative observational studies [11, 12, 14, 16]. Furthermore, none of the reviews included grey literature as sources of evidence. Consequently, potential reports of people's experiences were possibly excluded from those systematic reviews based primarily on study design selection criteria.

Therefore, the scoping review research synthesis method is warranted for our investigation. Scoping reviews 'serve a different purpose' than systematic reviews [30] and are utilised to examine the presence, extent, variety, and characteristics of the evidence. They are essentially exploratory and are not restricted to a focused research question and specific populations, interventions (exposures) and outcomes [30-32].

This is a protocol of a scoping review with an evidence map. In the absence of available mapping of the volume and content of literature regarding people's experiences regarding AIS, an evidence map study is also warranted [33]. Scoping studies are appropriate at initial stages of evidence mapping to

identifying knowledge gaps [30-32]. Both research synthesis methods 'share similarities' with regards to methodology and reporting guidelines [30, 33]. PRISMA-ScR applies both for scoping reviews and for evidence maps [31].

Objectives

We are interested in people's experiences, defined as both 'something that happens to you that affects how you feel' (the *passive* mode) and 'the process of getting knowledge or skill from doing, seeing, or feeling things' (the *active* mode) [34], related to AIS. In terms of Evidence-Based Practice [27-29] our aim is to map the evidence addressing people's experiences in terms of their perspectives, preferences, needs, and values, and not experience as a component of expertise of professionals delivering treatment and care.

The objectives of this scoping review are:

- to map and examine the extent, variety, and nature of the evidence addressing experiences related to AIS
- to explore the depth and the comprehensiveness of current understandings of people's experiences of AIS in everyday life and health and care contexts
- to identify knowledge gaps in this subject matter.

Hence, the main question of the study is: what is known from the available reports about experiences of all those touched by the problem of AIS, both directly and indirectly – taking into consideration both the natural history and the untreated AIS, and the management of this health condition.

METHODS AND ANALYSIS

Protocol design and reporting

We based our protocol on the Joanna Briggs Institute's (JBI) scoping review manual [32] and consulted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist and explanation paper [31]. Additionally, we referred to both the original Arksey and O'Malley's scoping review framework [35], and the methodological input from Levac and colleagues [36]. For the reporting of the protocol, we followed the JBI guidance [32], and consulted PRISMA-ScR [31, 37] as well as PRISMA for protocols (PRISMA-P) [38].

Eligibility criteria

We adopted the JBI's Population – Concept – Context (PCC) framework [32] to formulate the objectives and research questions, and also to conceptualise the study and report characteristics in terms of eligibility criteria. The PCC characteristics of our study are elaborated on in Table 1.

Table 1 Objectives and eligibility criteria for the review.

Objectives/ Inclusion criteria	Elaboration
Population/ types of participants: - people with adolescent idiopathic scoliosis (AIS) - their significant others - other people involved	- people diagnosed with AIS, regardless of their age - significant others: e.g. parents, siblings, friends, but also professionals in some cases - people involved in the management of AIS - sources that exclusively focus on other than AIS types of scoliosis (e. g. scoliosis related to other health conditions, early onset scoliosis) will not be considered
Concept/ phenomena of interest: - people's experience related to AIS - size and volume/ depth and breadth/ comprehensiveness of the body of literature regarding people's experience related to AIS	Information sources regarding quality of life, body image, mood, depression, anxiety, mental health, activities of daily living, and other medical and social issues will be considered for inclusion if provide experience-related body of evidence
Context/ setting: - everyday life - health care context	Country and culture: any country, regardless of cultural context (e.g. the issue of school screening is a subject of analyses in countries and cultures worldwide)

Eligible study designs. We will consider any quantitative, qualitative, and mixed-methods primary study designs, including different qualitative research methods like narrative, phenomenology, grounded theory, ethnography and case study, as well as any research synthesis reports. Narrative reviews and opinion pieces, including editorials, letters, debate, commentary, and viewpoint papers, will also be considered. Publications such as essays, diaries, newspaper articles, newsletters, blogs, fiction, will not be considered as eligible. We will provide a list of excluded studies and publications, with reasons for exclusion.

Other limits. Sources in English, Polish, Scandinavian, and German languages will be considered for inclusion. If found relevant (based on abstract, summary, table of contents, heading or introduction), for studies in Russian, French, and Chinese, we will consider inviting colleagues with relevant expertise for collaboration as interpreters. There will be no restriction as to publication date but in the charting process sources will be analysed as relevant to current practice or as historical, based on their publication date, content and context. Commercial information and information provided by sources having potential conflicts of interests (e.g. personal stories published on websites popularising diagnostic or treatment methods) will be excluded. We will not conduct searches of social networks and blogs. We will consider research papers concerning social media use addressing the objectives of our study.

Information sources

Given the subject matter, the characteristics of published relevant narrative reviews [1-3, 5, 7, 16], evidence synthesis reports [11, 12, 16], research recommendations [12, 17, 20], and based on our

preliminary searches, we assume that a search and selection process, including both academic and grey literature sources, is necessary for this study.

When deciding whether to qualify information sources as grey literature, we will follow the widely accepted 'Luxembourg definition' of grey literature as work that 'is produced on all levels of government, academia, business, and industry in print and electronic formats, but which is not controlled by commercial publishers, i.e. where publishing is not the primary activity of the producing body' [39]. We are also informed by the explanation of grey literature complementing the AMSTAR 2 tool for quality appraisal of systematic reviews [40].

Search strategy

We organised our exploratory search process into following stages: (1) academic literature search, (2) grey literature search, (3) complementary hand searches (snowballing searching) of the reference lists of the included publications, and (4) contacting authors.

Electronic bibliographic databases. To achieve satisfactory and required comprehensiveness and completeness of our searches, we need to conduct our searches both in a manner typical for scoliosis review studies – in medically oriented databases, and also in databases covering social sciences. We will search in general bibliographic and research synthesis databases. We will also search in databases provided by academic publishers as, especially for social science publications, we need to conduct searches in particular journals. Databases to be searched include PubMed, MEDLINE (via EBSCO), SportDiscus (via EBSCO), Web of Science including Social Sciences Citation Index, Scopus, ProQuest, PsycINFO, Social Sciences Full Text (EBSCO), JSTOR, GoogleScholar, Cochrane CENTRAL, Joanna Briggs Institute, Campbell Library, Epistemonikos, SpringerLink, ScienceDirect (Elsevier), Wiley Online Library and Taylor & Francis Online. The list may be extended by including other key publishing houses.

Grey literature. We formulated the following grey literature search strategy [40, 41]:

(1) Grey literature databases search: Open Grey, Proquest Dissertations & Thesis Global, New York Academy of Medicine's Grey Literature Report, Google Scholar, Web of Science
(2) The Grey Matters checklist
(3) Google search; we will search the first ten pages for the search hits (i.e. 100 records to be screened for each set of search terms), as a recommended method allowing to capture the most relevant records while maintaining feasibility
(4) Targeted web-based searches: websites of institutions, organisations, and patient groups.

We will conduct the grey literature search, after concluding the academic literature search , so that we will be better acquainted with the search and selection process.

Hand searching of the reference lists of the included publications will be done consecutively throughout the searching process.

Contacting the authors. We will contact key authors known to publish in this area for any additional published or unpublished work.

We will conduct the searches using all identified keywords and index terms. The initial search strategies for PubMed and for grey literature, including a list of selected websites, are presented as Supplementary file 1.

Selection of sources and data charting

Organisation of the process. The study team consists of two senior researchers, one of them with an expertise in scoliosis studies and in research synthesis methods, and one with expertise in

phenomenology and in qualitative studies. The third author is a doctoral candidate with a background in phenomenology and in qualitative studies.

We will apply the iterative team approach to selecting sources and for data charting from the included literature. The screening and study selection, as well as data charting will be undertaken by one reviewer and two verifiers, working independently. Then the reviewer and the verifiers will resolve discrepancies, if present, by discussion. If needed, we will invite two collaborators to support us with the data charting process.

Selection of sources. We will use two combined flow diagrams for academic and for grey literature search and selection processes, based directly on the PRISMA flowchart [42] and adapted from Godin et al [39], respectively. The results of both searches will be combined, and then, if applicable, supplemented with the results of the hand-searches of the reference lists. We will use a hand-search table for reporting results of hand-searches. The template flow diagrams and a template hand-search table are attached as Supplementary file 2.

Data charting framework. We will use a data charting table for the process of data charting from the included sources. Our aim is to use the form at the review stage, and we assume that the data charting process is iterative so that the charting table might be updated during the review process. The data charting form is attached as Supplementary file 3.

Calibration exercises. We will conduct pilot tests (calibration exercises) to ensure systematic and reproducible study selection, and to confirm satisfactory interrater agreements, as well as to familiarise the review team with the data charting form and to test the comprehensiveness of its content. The data charting form will be trialled on two reports [7, 10].

Characteristics of the included sources of evidence. We will present characteristics for which data were charted and will provide the citations for each source of evidence in an evidence summary table [31-33], corresponding to the data charting table. It will be presented in the final report to map the evidence regarding the objectives of this scoping review.

Protocol registration. We made our protocol publicly visible via the Open Science Framework (OSF) website (https://osf.io/3yr76/, created 07 02 2019).

Changes to the protocol. Giving the exploratory characteristics of the study, we can expect amendments to the search and selection process, and, consequently, to the data charting table during the review process. If done, this will be reported through the OSF registry and in the final report.

Key dates. We made our first attempts to this scoping review starting in November 2018, and conducted initial exploratory searches in February 2019. We expect to start the actual study in November 2019 and to prepare the report by July 2020.

DISCUSSION

The management of AIS needs to be considered, in terms of person-centred aspects of care, including people's experiences and everyday life beyond health professional settings. This scoping review is intended to supplement the body of evidence with a research synthesis report regarding people's experiences regarding AIS. Implementation of the wide and exploratory scoping review research synthesis method, rather than a systematic review approach, is ideal for that purpose.

The exploratory and open characteristics of the scoping review approach, both as regards methodology, and the subject matter of this study, allows us to conduct the review in an iterative, evolving way. Nonetheless, we faced some important issues at the stage of creating the protocol.

Conduct guidelines considerations. We chose the current JBI guidance [32] for scoping review conduct, as it is consistent with the PRISMA-ScR guidance [31], and it addresses, utilises, and improves earlier scoping review methodology proposals [33, 35, 36]. More importantly, the JBI model of Evidence-Based Health Care [29] corresponds with the concept of our study, with the principles of the evidence for feasibility, appropriateness, meaningfulness of interventions for specific populations, cultures and contexts, as being of equal value to the evidence of effectiveness. This model acknowledges the broad conceptualisation of evidence, with the pronunciation of varying sources of evidence.

Reporting guidelines considerations. We will follow the PRISMA-ScR reporting guidelines in the final report of the scoping review. As to the protocol reporting, PRISMA-P is the standard reporting guideline for systematic review protocols [38], while the only general guidance for the content of scoping review protocols is provided in the JBI manual [32]. Therefore, in order to specify the most accurate checklist and content of our protocol, we conducted a comparative exercise of the PRISMA-ScR (in two slightly differing versions [31, 37]) and the corresponding items of the PRISMA-P.

Application of results

This scoping review is intended to identify existing practice and research gaps to inform researchers, but also all those involved in the management and care of people diagnosed with AIS, including practitioners, policy makers, and interest groups and organisations in the field. Especially Primarily?, this scoping review can inform developers of recommendations and practice guidelines.

Limitations considerations

Methodological quality, risk of bias and strength of evidence. As our goal is to map the available publications, with minimal restrictions as to study designs, and with a wide grey literature search, in order to identify evidence gaps and research needs, we will not conduct a critical appraisal of the methodological quality or risk of bias within the included studies. Critical appraisal of individual sources of evidence is not a compulsory item of scoping reviews and is usually not done in such studies [31, 32]. For the same reasons, we are not going to conduct any syntheses of results or any assessment of the strength of the body of evidence.

Social media and blogs as sources of evidence. Despite potential large body of knowledge attainable from those sources, taking into account methodology guidance for scoping studies [32, 33, 35, 36], and probable difficulties in meaningful and sound analyses of such texts [43, 44], we assumed that including social media analyses is inapplicable within this review. A separate study is probably required for that task.

The **planned recipients** of the included sources of evidence (e.g. be it a peer-reviewed journal report produced as a scientific activity or a solicited report for a stakeholder, such as agency or a committee, or other policy maker), as well as study author affiliations (e.g. whether the authors are independent or connected to a scoliosis treatment clinic or to a spinal deformity scientific organisation or a group of professionals), are potential important factors in relation to the characteristics of the included sources of evidence, and their trustworthiness. We will describe those characteristics, as well as sources of funding for the included sources of evidence, in a text and in a separate table.

Evidence mapping. The graphical representation of evidence mapping in the final report will be done as tabular qualitative summaries and flow diagrams of the searching and selection processes, as well as tables containing characteristics of hand search results and characteristics of relevant websites and online materials, but not bubble plots. This is consistent with the characteristics and requirements for evidence maps [33].

Consultations. The optional, sixth stage of the scoping review framework (*Stage 6: Consultation*), as originally proposed by Arksey and O'Malley [35], involves consultations with key stakeholders in order to broaden the literature searching and selection process (i.e. to include further sources of knowledge indicated by the stakeholders) and to receive their feedback as to the findings of the scoping review. Our scoping review is, however, not intended to involve consultation with stakeholders for translating knowledge at this stage of the study. Our aim is to examine and to synthesise the body of literature, and to distribute the findings. The implementation and dissemination stage is too distant at this point.

Patient and public involvement. There was no patient or public involvement in the creation of this protocol and is not planned in the review, in accordance with the objectives of this study.

Ethic and dissemination

Scoping review is a type of a research synthesis, secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval.

The report of this scoping review will be submitted to a peer-reviewed journal. A dissemination of the findings among professionals involved in scoliosis management and policymaking is also planned.

Author Contributions. MP contributed with the idea of the review and proposed the design of the work. MP, EJ and WG conceptualized the study and MP and WG implemented the scoping review frameworks. MP drafted and edited the manuscript and the supplementary material, and EJ and WG revised it critically and contributed for its final version. All authors read and approved the final version of the manuscript.

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Competing interests. None declared.

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Supplementary file 1. Initial search strategy.

1. Academic literature search:

PubMed search strategy:

((((("scoliosis"[MeSH Terms] OR "scoliosis"[All Fields]) OR ("Spine Deform"[Journal] OR ("spine"[All Fields] AND "deformity"[All Fields]) OR "spine deformity"[All Fields]) OR (spinal[All Fields] AND ("congenital abnormalities"[MeSH Terms] OR ("congenital"[All Fields] AND "abnormalities"[All Fields]) OR "congenital abnormalities"[All Fields] OR "deformity"[All Fields])))) AND (("persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields]) OR ("persons"[MeSH Terms] OR "persons"[All Fields] OR "people"[All Fields]) OR ("parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields]) OR peer[All Fields] OR ("family"[MeSH Terms] OR "family"[All Fields])))) AND (experiences[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "opinions"[All Fields]) OR views[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "attitudes"[All Fields]) OR acceptance[All Fields] OR ("affect"[MeSH Terms] OR "affect"[All Fields] OR "mood"[All Fields]) OR ("depressive disorder"[MeSH Terms] OR ("depressive"[All Fields] AND "disorder"[All Fields]) OR "depressive disorder"[All Fields] OR "depression"[All Fields] OR "depression"[MeSH Terms]) OR ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields]) OR ("self concept"[MeSH Terms] OR ("self"[All Fields] AND "concept"[All Fields]) OR "self concept"[All Fields] OR ("self"[All Fields] AND "image"[All Fields]) OR "self image"[All Fields]) OR (("ego"[MeSH Terms] OR "ego"[All Fields] OR "self"[All Fields]) AND acceptance[All Fields]) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields]) OR ("motor activity"[MeSH Terms] OR ("motor"[All Fields] AND "activity"[All Fields]) OR "motor activity"[All Fields] OR "activity"[All Fields]) OR participation[All Fields])) AND idiopathic[All Fields]

2. Grey literature:

1. Targeted web-based searches (a template table with initial websites):

Website name/ organisation	link
Scoliosis Research Society, SRS	https://www.srs.org/
Society on Scoliosis Orthopaedic and Rehabilitation Treatment	http://sosort.mobi/index.php/en/
International Research Society for Spinal Deformities, IRSSD	https://www.irssd.org/
Physical and Rehabilitation Medicine Section and Board of the European Union of Medical Specialists	https://www.euro-prm.org/index.php?lang=en
UK National Screening Commitee	https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc
British Scoliosis Society	http://www.britscoliosissoc.org.uk/
British Scoliosis Research Foundation	http://www.bsrf.co.uk/
Scoliosis Australia	https://www.scoliosis-australia.org/
Spine Society of Australia	http://www.spinesociety.org.au/
Scoliosis Association of Australia	https://www.badbacks.com.au/info/links/back-care-health-australia-new-zealand/scoliosis-association-of-australia

Website name/ organisation	link
American Association of Neurological Surgeons, AANS	https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Scoliosis
Pediatric Orthopedic Society of North America, POSNA	https://posna.org/
National Scoliosis Foundation	www.scoliosis.org
Scoliosis Association	https://www.sauk.org.uk/
Setting Scoliosis Straight Foundation	http://www.settingscoliosisstraight.org/
Familydoctor.org (American Academy of Family Physicians)	https://familydoctor.org/condition/scoliosis/
Choosing Wisely (American Academy of Family Physicians)	https://www.aafp.org/about/initiatives/choosing-wisely.html
Healio	https://www.healio.com/pediatrics
MedlinePlus	
UpToDate	https://www.uptodate.com/contents/adolescent-idiopathic-scoliosis-clinical-features-evaluation-and-diagnosis
PracticeUpdate	https://www.practiceupdate.com/explore/

2. Google search engine:

Date searched:
Searches "All results" – first 10 pages, representing 1000 results screened:

#	search	# new potentially relevant records	# new full records analysed	total # new records
1	scoliosis AND experience			
2	scoliosis OR spine AND experience			
3	scoliosis AND story OR narrative OR narratives			
4	scoliosis OR spine AND story OR narrative OR narratives			
5	scoliosis AND opinion			
6	scoliosis OR spine AND opinion			
7	scoliosis AND quality of life			
8	scoliosis OR spine AND quality of life			
9	scoliosis AND perspective			
10	scoliosis OR spine AND perspective			
11	scoliosis AND activity OR participation			
12	scoliosis OR spine AND activity OR participation			

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Supplementary file 2. Selection of sources flow charts.

Figure S2a. Flow chart step 1 template for the selection of sources of evidence from academic sources.

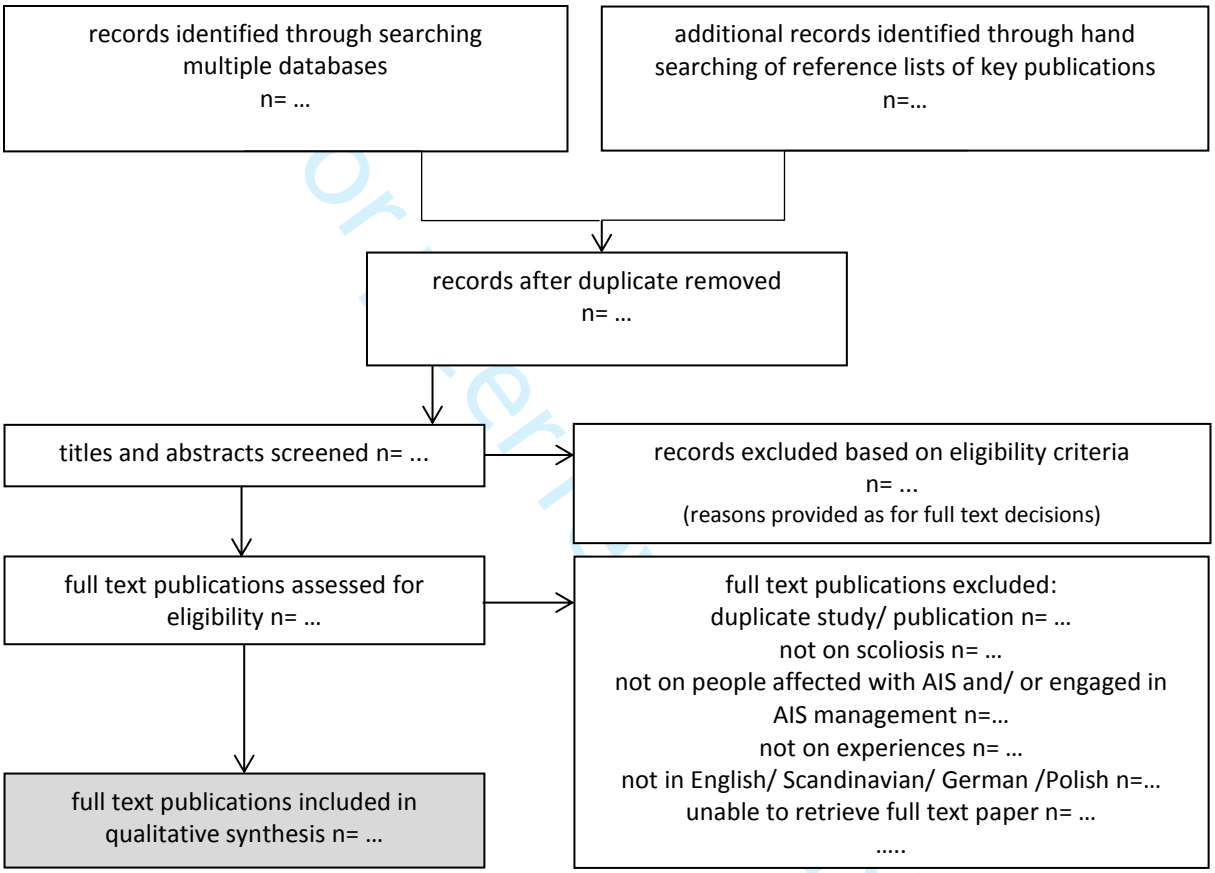

Figure S2b. Flow chart step 2 template for the selection of sources of evidence from grey literature. Adapted from Godin et al [syst rev 2015…], modified.

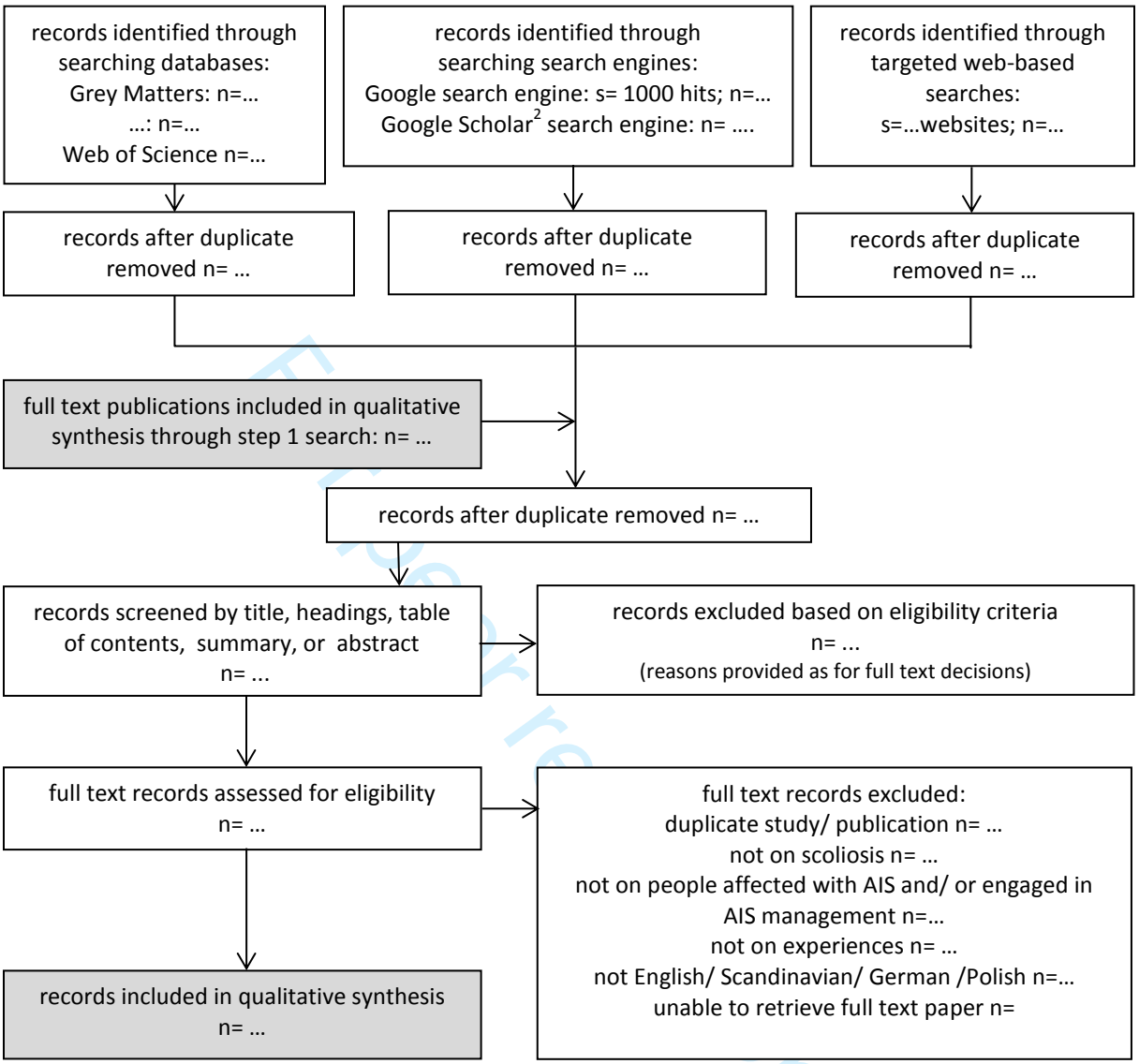

Table S2. Step 3 Hand search of the reference lists of key publications.

key publications included for reference list searching	reference screened for eligibility	decision	
		include	exclude, with reason
..			
..			

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Supplementary file 3. Data charting form.

Study Details and Characteristics:											
Citation:											
publication type:	academic:		grey:		unpublished:						
Type of study	primary:		secondary:		tertiary:		other:				
Study design:											
Origin/ country of origin: (where the study was conducted)											
Content:											
Aims/ objectives of the study:											
AIS as the problem:		Health conditions related to AIS as the problem:									
Diagnostics as the problem:		Screening as the problem:									
Treatment as the problem:		Other people as the problem:									
Cosmetics / appearance as the problem:		Other (e.g. physical activity/ sports/ lifestyle):									
Research questions (if applicable):											
Eligibility criteria:											
What is reported (e.g. views, opinions, experiences):											
Context:											
Country/ region/ state:											
Culture and societal aspects (e.g. education, religion, beliefs, norms):											
Setting (e.g. school, outpatient clinic, community/ home):											
Basis for the programme/ intervention/ treatment (national/ regional guidelines, statements, recommendations, individual programme, other):											
Scoliosis in the family:											
Other:											
Participants:											
affected person(s) ☐ relative(s) ☐ other person(s) (who):											
Age:		Number:									
Sex:		severity of AIS:									
Data on progression:											
Treated ☐		Untreated ☐									
Other characteristics (e.g. related to relatives/ other people, e.g. scoliosis in the family)											
Details/Results/ outcomes extracted from study (in relation to the **concept** of the scoping review):											
How diagnosed:											
Screening ☐		Visit ☐			Other (e.g. physiotherapist, leaflet used by parents):						
Type of treatment(s)/ intervention(s) ☐					experiences related to untreated persons ☐						

Length (and sequence, if applicable) of treatment(s):	
Primary (person-centred) outcomes:	
Related to effectiveness (e.g. hopes and expectations):	
Related to harms (e.g. stigma, labellisation, pain, discomfort):	
Related to time, daily routine, time management and finance:	
Other:	
Secondary outcomes (any related to the treatment process, as in biomedical literature:	
Effectiveness of intervention(s) (e.g. Cobb angle, progression):	
Harms (biomedical, e.g. x-ray exposure):	
Other:	
Additional information / notes:	
key findings that relate to the scoping review questions:	
gaps in the research/ practice:	

Date:

Reviewer:

BMJ Open

A Scoping Review Protocol to Map the Evidence of Experiences Related to Adolescent Idiopathic Scoliosis

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A Scoping Review Protocol to Map the Evidence of Experiences Related to Adolescent Idiopathic Scoliosis

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ABSTRACT

Introduction Adolescent idiopathic scoliosis, the diagnosis and management of this condition, may lead to poorer body image and diminished psychosocial functioning. Furthermore, treatment, especially bracing and surgery as well as screening, remain controversial and debated, with an unclear evidence-base. Personal experiences in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as highly valued. Nonetheless, people's experiences related to adolescent idiopathic scoliosis is an issue underrepresented in current systematic reviews and systematically developed recommendations. There appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications in this field. The objective of this planned scoping review is to explore and map the available evidence from various sources to address a broad question of what is known about experiences of all those touched, directly and indirectly, by the problem of adolescent idiopathic scoliosis.

Methods and analysis We based our protocol on the Joanna Briggs Institute's scoping review method, including the Population – Concept – Context framework, to formulate the objectives, research questions, eligibility criteria, and conduct characteristics of the study. We will consider any primary study designs, research synthesis reports, as well as narrative reviews and opinion pieces. We will not restrict eligible publications to English language. Search and selection processes will include academic and grey literature searches using multiple electronic databases, search engines and websites, hand searches, and contacting the authors. We will use a customised data charting table and present a narrative synthesis of the results.

Ethics and dissemination Scoping review is a secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval. We will submit the report to a peer-reviewed journal and disseminate it among professionals involved in scoliosis management, guideline and recommendation development, and policymaking.

ARTICLE SUMMARY

Strengths and limitations of this study

- This article outlines a protocol of the first research synthesis study focusing on people's experiences related to adolescent idiopathic scoliosis, an issue underrepresented in current systematic reviews and systematically developed recommendations in this field.
- The scoping review characteristics, multiple database and hand searches for academic and grey literature, will increase the likelihood of thorough mapping of the evidence concerning this person-centred subject matter.
- We will use the Joanna Briggs Institute's Problem – Content – Context framework for the selection and analysis of the literature, and study report formulation.
- In addition to standard requirements for scoping review studies, to increase the trustworthiness of our findings, we will conduct critical appraisals of the included publications.
- For methodological and practical reasons, we will not consider sources from social networks and blogs, which is a potential limitation, giving the subject matter of our study.

INTRODUCTION

Adolescent idiopathic scoliosis (AIS) is a complex health condition that is defined as a lateral spine curvature of 10º or more, of an unknown origin, that manifests in children older than ten years of age [1-3]. Mild AIS is present in about 1.5 – 3% of adolescents, while more severe curves exceeding 40º are found in 0.04 – 0.3 %. The female to male ratio ranges from about 1.4:1 for curves of less than 20° to 7.2:1 for curves exceeding 40° [4].

This structural deformity of the spine and trunk, depending on its severity, may lead to pain and pulmonary or cardiac complications [1-4]. On the other hand, this health condition, but potentially also the diagnosis and treatment, may be associated with lower self-esteem and poorer body image, as well as worse psychosocial functioning [1, 5-7]. All these may also touch significant others [8, 9]. Treatment of AIS, especially bracing and surgery, are controversial as regards side effects and harms, with inconsistent evidence-base [1, 5, 6, 10-14]. Routine screening for scoliosis is also debated, with conflicting recommendations [15-17]. The evidence-base for both screening and treatment is very unclear [13, 14, 16, 18].

Based on recent comprehensive systematic reviews [13, 14], impactful narrative reviews [1-3], and tertiary evidence synthesis studies [16, 18], little is considered and understood about what the people diagnosed with, and treated for, AIS, their significant others, and other people, experience about this condition. Furthermore, there appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications [14, 16, 18]. It is especially significant as this health problem emerges in a fragile time of puberty and adolescence and as ethical doubts have been raised concerning management of AIS [6, 13, 17]. The recommendations for research and management of AIS [19-22] seem to uphold this state of affairs.

This is striking in the Evidence-Based Practice perspective, since recommendation formulation principles have evolved in recent years [23-25]. Experiences of people, in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as principal and highly valued [26-28]. The Evidence-Based Practice triad addresses expertise of professionals, evidence for effectiveness and safety of interventions, but also a person's perspectives, with their opinions, attitudes, values, and views [29, 30]. Those perspectives are also important in terms of the acceptance of treatment, an issue discussed in scoliosis management as being crucial and problematic [1, 6, 18]. More generally, personal factors concerning illness as a perceived, personal experience, in contrast to disease as a medical term [23, 27, 29, 31], are vital as regards management of AIS. A better understanding of these aspects needs to be opened with mapping of evidence.

Why scoping review. To the best of our knowledge, research syntheses addressing various aspects of AIS, typically apply the standard method of systematic review of intervention studies, and are based exclusively on the evidence from controlled trials and quantitative observational studies [13, 14, 16, 18]. Furthermore, none of the reviews included grey literature as sources of evidence. Consequently, potential reports of people's experiences were possibly excluded from those systematic reviews based primarily on study design selection criteria.

Therefore, the scoping review research synthesis method is warranted for our investigation. Scoping reviews 'serve a different purpose' than systematic reviews [32] and are utilised to examine the presence, extent, variety, and characteristics of the evidence. They are essentially exploratory and are not restricted to a focused research question and specific populations, interventions (exposures) and outcomes [32-34].

This is a protocol of a scoping review with an evidence map. In the absence of available mapping of the volume and content of literature regarding people's experiences regarding AIS, an evidence map

study is also warranted [35]. Scoping studies are appropriate at initial stages of evidence mapping to identifying knowledge gaps [32-34]. Both research synthesis methods 'share similarities' with regards to methodology and reporting guidelines [32, 35]. PRISMA-ScR applies both for scoping reviews and for evidence maps [33].

Objectives

We are interested in people's experiences, defined as both 'something that happens to you that affects how you feel' (the *passive* mode) and 'the process of getting knowledge or skill from doing, seeing, or feeling things' (the *active* mode) [36], related to AIS. In terms of Evidence-Based Practice [29-31] our aim is to map the evidence addressing people's experiences in terms of their perspectives, preferences, needs, and values. This scoping review is **not** intended to address the term 'experience' understood as **a component of expertise** of professionals delivering treatment and care, *gained through the years of training and routine*.

The objectives of this scoping review are:

- to map and examine the extent, variety, and nature of the evidence addressing experiences related to AIS
- to explore the depth and the comprehensiveness of current understandings of people's experiences of AIS in everyday life and health and care contexts
- to identify knowledge gaps in this subject matter.

Hence, the main question of the study is: what is known from the available reports about experiences of all those touched by the problem of AIS, both directly and indirectly – taking into consideration both the natural history and the untreated AIS, and the management of this health condition.

METHODS AND ANALYSIS

Protocol design and reporting

We based our protocol on the Joanna Briggs Institute's (JBI) scoping review manual [34] and consulted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist and explanation paper [33]. Additionally, we referred to both the original Arksey and O'Malley's scoping review framework [37], and the methodological input from Levac and colleagues [38]. For the reporting of the protocol, we followed the JBI guidance [34], and consulted PRISMA-ScR [33, 39] as well as PRISMA for protocols (PRISMA-P) [40].

Eligibility criteria

We adopted the JBI's Population – Concept – Context (PCC) framework [34] to formulate the objectives and research questions, and also to conceptualise the study and report characteristics in terms of eligibility criteria. The PCC characteristics of our study are elaborated on in Table 1.

Table 1 Objectives and eligibility criteria for the review.

Objectives/ Inclusion criteria	Elaboration
Population/ types of participants: - people with adolescent idiopathic scoliosis (AIS) - their significant others - other people involved	- people diagnosed with AIS, regardless of their age - significant others: e.g. parents, siblings, friends, but also professionals in some cases - people involved in the management of AIS - sources that exclusively focus on other than AIS types of scoliosis (e. g. scoliosis related to other health conditions, early onset scoliosis) will not be considered
Concept/ phenomena of interest: - people's experience related to AIS - size and volume/ depth and breadth/ comprehensiveness of the body of literature regarding people's experience related to AIS	Information sources regarding quality of life, body image, mood, depression, anxiety, mental health, activities of daily living, and other medical and social issues will be considered for inclusion if provide experience-related body of evidence
Context/ setting: - everyday life - health care context	Country and culture: any country, regardless of cultural context (e.g. the issue of school screening is a subject of analyses in countries and cultures worldwide)

Eligible study designs. We will consider any quantitative, qualitative, and mixed-methods primary study designs, including different qualitative research methods like narrative, phenomenology, grounded theory, ethnography and case study, as well as any research synthesis reports. Narrative reviews and opinion pieces, including editorials, letters, debate, commentary, and viewpoint papers, will also be considered. Publications such as essays, diaries, newspaper articles, newsletters, blogs, fiction, will not be considered as eligible. We will provide a list of excluded studies and publications, with reasons for exclusion.

Other limits. Sources in English, Polish, Scandinavian, and German languages will be considered for inclusion. If found relevant (based on abstract, summary, table of contents, heading or introduction), for studies in Russian, French, and Chinese, we will consider inviting colleagues with relevant expertise for collaboration as interpreters. There will be no restriction as to publication date but in the charting process sources will be analysed as relevant to current practice or as historical, based on their publication date, content and context. Commercial information and information provided by sources having potential conflicts of interests (e.g. personal stories published on websites popularising diagnostic or treatment methods) will be excluded. We will not conduct searches of social networks and blogs. We will consider research papers concerning social media use addressing the objectives of our study.

Information sources

Given the subject matter, the characteristics of published relevant narrative reviews [1-3, 5, 7, 18], evidence synthesis reports [13, 14, 18], research recommendations [14, 19, 22], and based on our

preliminary searches, we assume that a search and selection process, including both academic and grey literature sources, is necessary for this study.

When deciding whether to qualify information sources as grey literature, we will follow the widely accepted 'Luxembourg definition' of grey literature as work that 'is produced on all levels of government, academia, business, and industry in print and electronic formats, but which is not controlled by commercial publishers, i.e. where publishing is not the primary activity of the producing body' [41]. We are also informed by the explanation of grey literature complementing the AMSTAR 2 tool for quality appraisal of systematic reviews [42].

Search strategy

We organised our exploratory search process into following stages: (1) academic literature search, (2) grey literature search, (3) complementary hand searches (snowballing searching) of the reference lists of the included publications, and (4) contacting authors.

Electronic bibliographic databases. To achieve satisfactory and required comprehensiveness and completeness of our searches, we need to conduct our searches both in a manner typical for scoliosis review studies – in medically oriented databases, and also in databases covering social sciences. We will search in general bibliographic and research synthesis databases. We will also search in databases provided by academic publishers as, especially for social science publications, we need to conduct searches in particular journals. Databases to be searched include PubMed, MEDLINE (via EBSCO), SportDiscus (via EBSCO), Web of Science including Social Sciences Citation Index, Scopus, ProQuest, PsycINFO, Social Sciences Full Text (EBSCO), JSTOR, GoogleScholar, Cochrane CENTRAL, Joanna Briggs Institute, Campbell Library, Epistemonikos, SpringerLink, ScienceDirect (Elsevier), Wiley Online Library and Taylor & Francis Online. The list may be extended by including other key publishing houses.

Grey literature. We formulated the following grey literature search strategy [42, 43]:

(1) Grey literature databases search: Open Grey, Proquest Dissertations & Thesis Global, New York Academy of Medicine's Grey Literature Report, Google Scholar, Web of Science
(2) The Grey Matters checklist
(3) Google search; we will search the first ten pages for the search hits (i.e. 100 records to be screened for each set of search terms), as a recommended method allowing to capture the most relevant records while maintaining feasibility
(4) Targeted web-based searches: websites of institutions, organisations, and patient groups.

We will conduct the grey literature search, after concluding the academic literature search , so that we will be better acquainted with the search and selection process.

Hand searching of the reference lists of the included publications will be done consecutively throughout the searching process.

Contacting the authors. We will contact key authors known to publish in this area for any additional published or unpublished work.

We will conduct the searches using all identified keywords and index terms. The initial search strategies for PubMed and for grey literature, including a list of selected websites, are presented as Supplementary file 1.

Selection of sources, critical appraisal and data charting

Organisation of the process. The study team consists of two senior researchers, one of them with an expertise in scoliosis studies and in research synthesis methods, and one with expertise in

phenomenology and in qualitative studies. The third author is a doctoral candidate with a background in phenomenology and in qualitative studies.

We will apply the iterative team approach to selecting sources, for data charting from and critical appraisal of the included literature. The screening and study selection, as well as data charting and critical appraisals will be undertaken by one reviewer and two verifiers, working independently. Then the reviewer and the verifiers will resolve discrepancies, if present, by discussion. If needed, we will invite two collaborators to support us with the data charting process.

Selection of sources. We will use two combined flow diagrams for academic and for grey literature search and selection processes, based directly on the PRISMA flowchart [44] and adapted from Godin et al [41], respectively. The results of both searches will be combined, and then, if applicable, supplemented with the results of the hand-searches of the reference lists. We will use a hand-search table for reporting results of hand-searches. The template flow diagrams and a template hand-search table are attached as Supplementary file 2.

Data charting framework. We will use a data charting table for the process of data charting from the included sources. Our aim is to use the form at the review stage, and we assume that the data charting process is iterative so that the charting table might be updated during the review process. The data charting form is attached as Supplementary file 3.

Methodological quality appraisal.

During the data charting process, we will additionally assess methodological quality of the included literature. We will use the Mixed Methods Appraisal Tool (MMAT), version 2018 [45], which is designed to appraise the methodological quality of empirical studies – qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies, as well as the Joanna Briggs Institute Checklist for Text and Opinion [46] for theoretical or opinion publications. For systematic reviews of randomised or non-randomised studies of interventions, we will apply the AMSTAR 2 [42] tool.

Calibration exercises. We will conduct pilot tests (calibration exercises) to ensure systematic and reproducible study selection, and to confirm satisfactory interrater agreements, as well as to familiarise the review team with the data charting form and to test the comprehensiveness of its content. The data charting form will be trialled on two reports [7, 12].

Characteristics of the included sources of evidence. We will present characteristics for which data were charted and will provide the citations for each source of evidence in an evidence summary table [33-35], corresponding to the data charting table. It will be presented in the final report to map the evidence regarding the objectives of this scoping review.

Protocol registration. We made our protocol publicly visible via the Open Science Framework (OSF) website (https://osf.io/3yr76/, created 07 02 2019).

Changes to the protocol. Giving the exploratory characteristics of the study, we can expect amendments to the search and selection process, and, consequently, to the data charting table during the review process. If done, this will be reported through the OSF registry and in the final report.

Key dates. We made our first attempts to this scoping review starting in November 2018, and conducted initial exploratory searches in February 2019. We expect to start the actual study in November 2019 and to prepare the report by July 2020.

Patient and public involvement. There was no patient or public involvement in the creation of this protocol and is not planned in the review, in accordance with the objectives of this study.

DISCUSSION

The management of AIS needs to be considered, in terms of person-centred aspects of care, including people's experiences and everyday life beyond health professional settings. This scoping review is intended to supplement the body of evidence with a research synthesis report regarding people's experiences regarding AIS. Implementation of the wide and exploratory scoping review research synthesis method, rather than a systematic review approach, is ideal for that purpose.

The exploratory and open characteristics of the scoping review approach, both as regards methodology, and the subject matter of this study, allows us to conduct the review in an iterative, evolving way. Nonetheless, we faced some important issues at the stage of creating the protocol.

Conduct guidelines considerations. We chose the current JBI guidance [34] for scoping review conduct, as it is consistent with the PRISMA-ScR guidance [33], and it addresses, utilises, and improves earlier scoping review methodology proposals [35, 37, 38]. More importantly, the JBI model of Evidence-Based Health Care [31] corresponds with the concept of our study, with the principles of the evidence for feasibility, appropriateness, meaningfulness of interventions for specific populations, cultures and contexts, as being of equal value to the evidence of effectiveness. This model acknowledges the broad conceptualisation of evidence, with the pronunciation of varying sources of evidence.

Reporting guidelines considerations. We will follow the PRISMA-ScR reporting guidelines in the final report of the scoping review. As to the protocol reporting, PRISMA-P is the standard reporting guideline for systematic review protocols [40], while the only general guidance for the content of scoping review protocols is provided in the JBI manual [34]. Therefore, in order to specify the most accurate checklist and content of our protocol, we conducted a comparative exercise of the PRISMA-ScR (in two slightly differing versions [33, 39]) and the corresponding items of the PRISMA-P.

Application of results

This scoping review is intended to identify existing practice and research gaps to inform researchers, but also all those involved in the management and care of people diagnosed with AIS, including practitioners, policy makers, and interest groups and organisations in the field. Especially, this scoping review can inform developers of recommendations and practice guidelines.

Strengths and limitations considerations

Methodological quality, risk of bias and strength of evidence. Our goal is to map the available publications, with minimal restrictions as to study designs, and with a wide grey literature search, in order to identify evidence gaps and research needs. Critical appraisal of the methodological quality or risk of bias within the individual sources of evidence is not expected for scoping reviews [33, 34, 38] Nonetheless, to strengthen the trustworthiness of our study, we will conduct a critical appraisal of the included individual publications. . We are not going to conduct any syntheses of results or any assessment of the overall strength of the body of evidence.

Social media and blogs as sources of evidence. Despite potential large body of knowledge attainable from those sources, taking into account methodology guidance for scoping studies [34, 35, 37, 38], and probable difficulties in meaningful and sound analyses of such texts [47, 48], we assumed that including social media analyses is inapplicable within this review. A separate study is probably required for that task.

The **planned recipients** of the included sources of evidence (e.g. be it a peer-reviewed journal report produced as a scientific activity or a solicited report for a stakeholder, such as agency or a committee, or other policy maker), as well as study author affiliations (e.g. whether the authors are independent or connected to a scoliosis treatment clinic or to a spinal deformity scientific organisation or a group of professionals), are potential important factors in relation to the characteristics of the included sources of evidence, and their trustworthiness. We will describe those characteristics, as well as sources of funding for the included sources of evidence, in a text and in a separate table.

Evidence mapping. The graphical representation of evidence mapping in the final report will be done as tabular qualitative summaries and flow diagrams of the searching and selection processes, as well as tables containing characteristics of hand search results and characteristics of relevant websites and online materials, but not bubble plots. This is consistent with the characteristics and requirements for evidence maps [35].

Consultations. The optional, sixth stage of the scoping review framework (*Stage 6: Consultation*), as originally proposed by Arksey and O'Malley [37], involves consultations with key stakeholders in order to broaden the literature searching and selection process (i.e. to include further sources of knowledge indicated by the stakeholders) and to receive their feedback as to the findings of the scoping review. Our scoping review is, however, not intended to involve consultation with stakeholders for translating knowledge at this stage of the study. Our aim is to examine and to synthesise the body of literature, and to distribute the findings. The implementation and dissemination stage is too distant at this point.

Ethic and dissemination

Scoping review is a type of a research synthesis, secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval.

The report of this scoping review will be submitted to a peer-reviewed journal. A dissemination of the findings among professionals involved in scoliosis management and policymaking is also planned.

Author Contributions. MP contributed with the idea of the review and proposed the design of the work. MP, EJ and WG conceptualized the study and MP and WG implemented the scoping review frameworks. MP drafted and edited the manuscript and the supplementary material, and EJ and WG revised it critically and contributed for its final version. All authors read and approved the final version of the manuscript.

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Competing interests. None declared.

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Supplementary file 1. Initial search strategy.

1. Academic literature search:

PubMed search strategy:

((((("scoliosis"[MeSH Terms] OR "scoliosis"[All Fields]) OR ("Spine Deform"[Journal] OR ("spine"[All Fields] AND "deformity"[All Fields]) OR "spine deformity"[All Fields]) OR (spinal[All Fields] AND ("congenital abnormalities"[MeSH Terms] OR ("congenital"[All Fields] AND "abnormalities"[All Fields]) OR "congenital abnormalities"[All Fields] OR "deformity"[All Fields])))) AND (("persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields]) OR ("persons"[MeSH Terms] OR "persons"[All Fields] OR "people"[All Fields]) OR ("parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields]) OR peer[All Fields] OR ("family"[MeSH Terms] OR "family"[All Fields])))) AND (experiences[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "opinions"[All Fields]) OR views[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "attitudes"[All Fields]) OR acceptance[All Fields] OR ("affect"[MeSH Terms] OR "affect"[All Fields] OR "mood"[All Fields]) OR ("depressive disorder"[MeSH Terms] OR ("depressive"[All Fields] AND "disorder"[All Fields]) OR "depressive disorder"[All Fields] OR "depression"[All Fields] OR "depression"[MeSH Terms]) OR ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields]) OR ("self concept"[MeSH Terms] OR ("self"[All Fields] AND "concept"[All Fields]) OR "self concept"[All Fields] OR ("self"[All Fields] AND "image"[All Fields]) OR "self image"[All Fields]) OR (("ego"[MeSH Terms] OR "ego"[All Fields] OR "self"[All Fields]) AND acceptance[All Fields]) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields]) OR ("motor activity"[MeSH Terms] OR ("motor"[All Fields] AND "activity"[All Fields]) OR "motor activity"[All Fields] OR "activity"[All Fields]) OR participation[All Fields])) AND idiopathic[All Fields]

2. Grey literature:

1. Targeted web-based searches (a template table with initial websites):

Website name/ organisation	link
Scoliosis Research Society, SRS	https://www.srs.org/
Society on Scoliosis Orthopaedic and Rehabilitation Treatment	http://sosort.mobi/index.php/en/
International Research Society for Spinal Deformities, IRSSD	https://www.irssd.org/
Physical and Rehabilitation Medicine Section and Board of the European Union of Medical Specialists	https://www.euro-prm.org/index.php?lang=en
UK National Screening Commitee	https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc
British Scoliosis Society	http://www.britscoliosissoc.org.uk/
British Scoliosis Research Foundation	http://www.bsrf.co.uk/
Scoliosis Priority Setting Partnership	http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/
Scoliosis Australia	https://www.scoliosis-australia.org/
Spine Society of Australia	http://www.spinesociety.org.au/
Scoliosis Association of Australia	https://www.badbacks.com.au/info/links/back-care-

Website name/ organisation	link
	health-australia-new-zealand/scoliosis-association-of-australia
American Association of Neurological Surgeons, AANS	https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Scoliosis
Pediatric Orthopedic Society of North America, POSNA	https://posna.org/
National Scoliosis Foundation	www.scoliosis.org
Scoliosis Association	https://www.sauk.org.uk/
Setting Scoliosis Straight Foundation	http://www.settingscoliosisstraight.org/
Familydoctor.org (American Academy of Family Physicians)	https://familydoctor.org/condition/scoliosis/
Choosing Wisely (American Academy of Family Physicians)	https://www.aafp.org/about/initiatives/choosing-wisely.html
Healio	https://www.healio.com/pediatrics
MedlinePlus	
UpToDate	https://www.uptodate.com/contents/adolescent-idiopathic-scoliosis-clinical-features-evaluation-and-diagnosis
PracticeUpdate	https://www.practiceupdate.com/explore/

2. Google search engine:

Date searched:
Searches “All results” – first 10 pages, representing 1000 results screened:

#	search	# new potentially relevant records	# new full records analysed	total # new records
1	scoliosis AND experience			
2	scoliosis OR spine AND experience			
3	scoliosis AND story OR narrative OR narratives			
4	scoliosis OR spine AND story OR narrative OR narratives			
5	scoliosis AND opinion			
6	scoliosis OR spine AND opinion			
7	scoliosis AND quality of life			
8	scoliosis OR spine AND quality of life			
9	scoliosis AND perspective			
10	scoliosis OR spine AND perspective			
11	scoliosis AND activity OR participation			
12	scoliosis OR spine AND activity OR participation			

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Supplementary file 2. Selection of sources flow charts.

Figure S2a. Flow chart step 1 template for the selection of sources of evidence from academic sources.

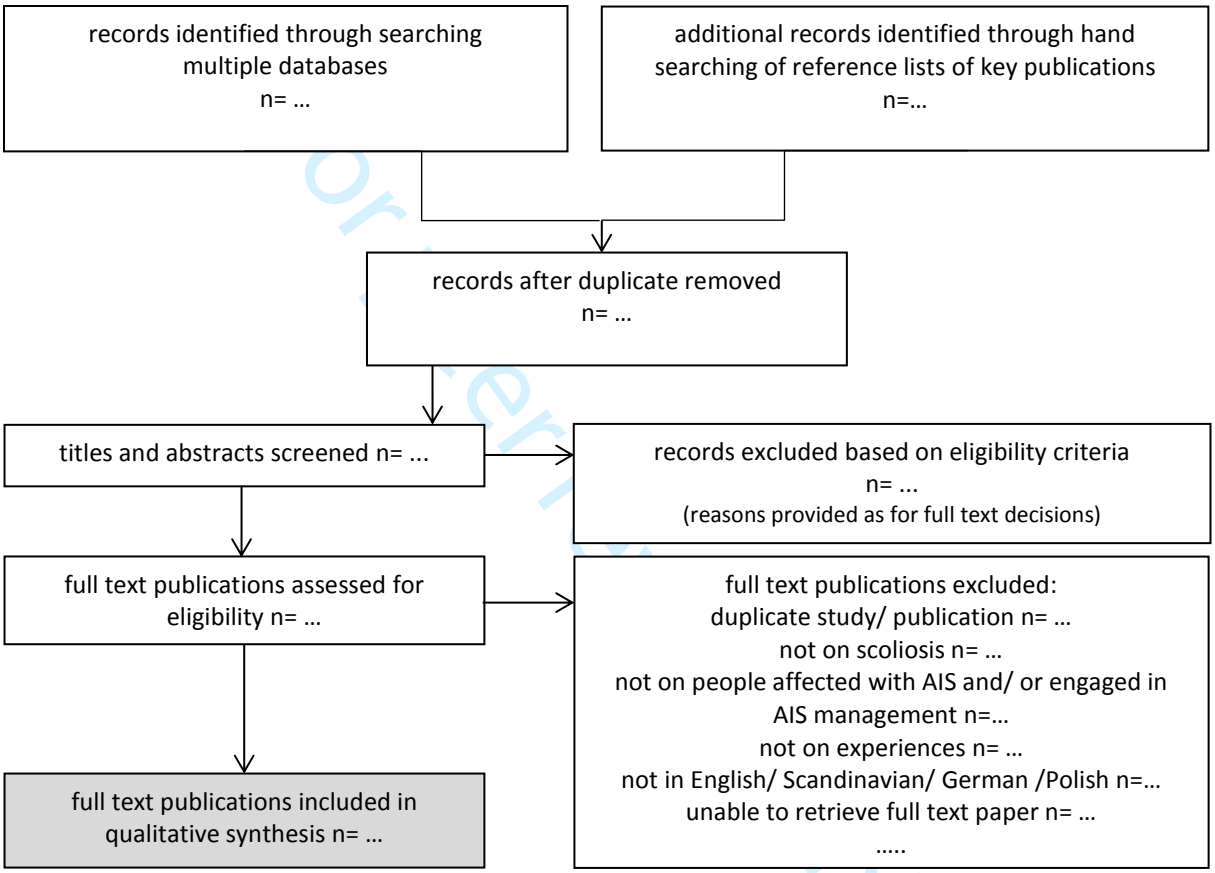

Figure S2b. Flow chart step 2 template for the selection of sources of evidence from grey literature. Adapted from Godin et al [syst rev 2015…], modified.

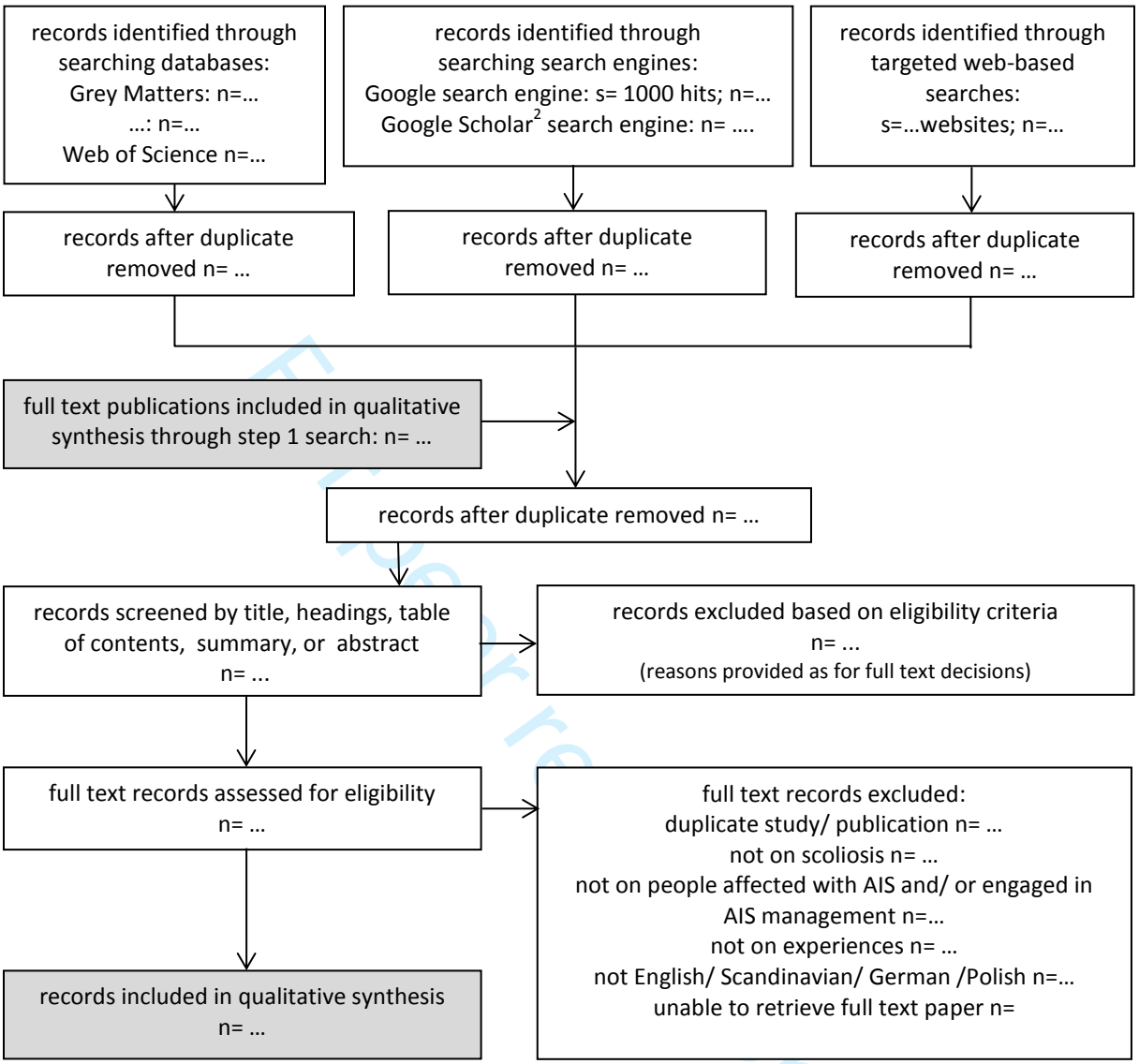

Table S2. Step 3 Hand search of the reference lists of key publications.

key publications included for reference list searching	reference screened for eligibility	decision	
		include	exclude, with reason
..			
..			

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Supplementary file 3. Data charting form.

Study Details and Characteristics:											
Citation:											
publication type:	academic:		grey:		unpublished:						
Type of study	primary:		secondary:		tertiary:		other:				
Study design:											
Origin/ country of origin: (where the study was conducted)											
Content:											
Aims/ objectives of the study:											
AIS as the problem:		Health conditions related to AIS as the problem:									
Diagnostics as the problem:		Screening as the problem:									
Treatment as the problem:		Other people as the problem:									
Cosmetics / appearance as the problem:		Other (e.g. physical activity/ sports/ lifestyle):									
Research questions (if applicable):											
Eligibility criteria:											
What is reported (e.g. views, opinions, experiences):											
How 'experience' is used (definition / understanding)											
Context:											
Country/ region/ state:											
Culture and societal aspects (e.g. education, religion, beliefs, norms):											
Setting (e.g. school, outpatient clinic, community/ home):											
Basis for the programme/ intervention/ treatment (national/ regional guidelines, statements, recommendations, individual programme, other):											
Scoliosis in the family:											
Other:											
Participants:											
affected person(s) ☐ relative(s) ☐ other person(s) (who):											
Age:		Number:									
Sex:		severity of AIS:									
Data on progression:											
Treated ☐		Untreated ☐									
Other characteristics (e.g. related to relatives/ other people, e.g. scoliosis in the family)											
Details/Results/ outcomes extracted from study (in relation to the **concept** of the scoping review):											
How diagnosed:											
Screening ☐	Visit ☐	Other (e.g. physiotherapist, leaflet used by parents):									
Diagnostic imaging:	YES / NO	Details, if YES (e.g. device, dose, no of exposures, area):									

Type of treatment(s)/ intervention(s) □	experiences related to untreated persons □
Length (and sequence, if applicable) of treatment(s):	
Primary (person-centred) outcomes:	
Related to effectiveness (e.g. hopes and expectations):	
Related to harms (e.g. stigma, labellisation, pain, discomfort, x-ray exposure):	
Related to time, daily routine, time management and finance:	
Other:	
Secondary outcomes (any related to the treatment process, as in biomedical literature):	
Effectiveness of intervention(s) (e.g. Cobb angle, progression):	
Harms (biomedical, e.g. x-ray exposure):	
Other:	
Additional information / notes:	
key findings that relate to the scoping review questions:	
gaps in the research/ practice:	

Date:

Reviewer:

BMJ Open

A Scoping Review Protocol to Map the Evidence of Experiences Related to Adolescent Idiopathic Scoliosis

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2019-032865.R2
Article Type:	Protocol
Date Submitted by the Author:	14-Oct-2019
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Secondary Subject Heading:	Paediatrics, Qualitative research, Research methods
Keywords:	adolescent idiopathic scoliosis, personal experiences, scoping review, evidence map

A Scoping Review Protocol to Map the Evidence of Experiences Related to Adolescent Idiopathic Scoliosis

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Keywords: adolescent idiopathic scoliosis, personal experiences, scoping review, evidence map

ABSTRACT

Introduction Adolescent idiopathic scoliosis, the diagnosis and management of this condition, may lead to poorer body image and diminished psychosocial functioning. Furthermore, treatment, especially bracing and surgery as well as screening, remain controversial and debated, with an unclear evidence-base. Personal experiences in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as highly valued. Nonetheless, people's experiences related to adolescent idiopathic scoliosis is an issue underrepresented in current systematic reviews and systematically developed recommendations. There appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications in this field. The objective of this planned scoping review is to explore and map the available evidence from various sources to address a broad question of what is known about experiences of all those touched, directly and indirectly, by the problem of adolescent idiopathic scoliosis.

Methods and analysis We based our protocol on the Joanna Briggs Institute's scoping review method, including the Population – Concept – Context framework, to formulate the objectives, research questions, eligibility criteria, and conduct characteristics of the study. We will consider any primary study designs, research synthesis reports, as well as narrative reviews and opinion pieces. We will not restrict eligible publications to English language. Search and selection processes will include academic and grey literature searches using multiple electronic databases, search engines and websites, hand searches, and contacting the authors. We will use a customised data charting table and present a narrative synthesis of the results.

Ethics and dissemination Scoping review is a secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval. We will submit the report to a peer-reviewed journal and disseminate it among professionals involved in scoliosis management, guideline and recommendation development, and policymaking.

ARTICLE SUMMARY

Strengths and limitations of this study

- This article outlines a protocol of the first research synthesis study focusing on people's experiences related to adolescent idiopathic scoliosis, an issue underrepresented in current systematic reviews and systematically developed recommendations in this field.
- The scoping review characteristics, multiple database and hand searches for academic and grey literature, will increase the likelihood of thorough mapping of the evidence concerning this person-centred subject matter.
- We will use the Joanna Briggs Institute's Problem – Content – Context framework for the selection and analysis of the literature, and study report formulation.
- In addition to standard requirements for scoping review studies, to increase the trustworthiness of our findings, we will conduct critical appraisals of the included publications.
- For methodological and practical reasons, we will not consider sources from social networks and blogs, which is a potential limitation, giving the subject matter of our study.

INTRODUCTION

Adolescent idiopathic scoliosis (AIS) is a complex health condition that is defined as a lateral spine curvature of 10º or more, of an unknown origin, that manifests in children older than ten years of age [1-3]. Mild AIS is present in about 1.5 – 3% of adolescents, while more severe curves exceeding 40º are found in 0.04 – 0.3 %. The female to male ratio ranges from about 1.4:1 for curves of less than 20° to 7.2:1 for curves exceeding 40° [4].

This structural deformity of the spine and trunk, depending on its severity, may lead to pain and pulmonary or cardiac complications [1-4]. On the other hand, this health condition, but potentially also the diagnosis and treatment, may be associated with lower self-esteem and poorer body image, as well as worse psychosocial functioning [1, 5-7]. All these may also touch significant others [8, 9]. Treatment of AIS, especially bracing and surgery, are controversial as regards side effects and harms, with inconsistent evidence-base [1, 5, 6, 10-14]. Even diagnostic imaging methods, and minimal spine and trunk asymmetry and deformity criteria, as well as cut-off points for the diagnosis of the condition, are under discussion in this context [13-15]. Routine screening for scoliosis is also debated, with conflicting recommendations [16-18]. The evidence-base for both screening and treatment is very unclear [14, 15, 17, 19].

Based on recent comprehensive systematic reviews [13, 14], impactful narrative reviews [1-3], and tertiary evidence synthesis studies [17, 19], little is considered and understood about what the people diagnosed with, and treated for, AIS, their significant others, and other people, experience about this condition. Furthermore, there appears a substantial imbalance between a vast amount of biomedical research reports, and sporadic bio-psycho-social publications [14, 17, 19]. It is especially significant as this health problem emerges in a fragile time of puberty and adolescence and as ethical doubts have been raised concerning management of AIS [6, 13, 18]. The recommendations for research and management of AIS [20-23] seem to uphold this state of affairs.

This is striking in the Evidence-Based Practice perspective, since recommendation formulation principles have evolved in recent years [24-26]. Experiences of people, in terms of issues such as person-centred care, shared decision making, and patient and public involvement, are contemporarily recognised as principal and highly valued [27-29]. The Evidence-Based Practice triad addresses expertise of professionals, evidence for effectiveness and safety of interventions, but also a person's perspectives, with their opinions, attitudes, values, and views [30, 31]. Those perspectives are also important in terms of the acceptance of treatment, an issue discussed in scoliosis management as being crucial and problematic [1, 6, 19]. More generally, personal factors concerning illness as a perceived, personal experience, in contrast to disease as a medical term [24, 28, 30, 32], are vital as regards management of AIS. A better understanding of these aspects needs to be opened with mapping of evidence.

Why scoping review. To the best of our knowledge, research syntheses addressing various aspects of AIS, typically apply the standard method of systematic review of intervention studies, and are based exclusively on the evidence from controlled trials and quantitative observational studies [13, 14, 17, 19]. Furthermore, none of the reviews included grey literature as sources of evidence. Consequently, potential reports of people's experiences were possibly excluded from those systematic reviews based primarily on study design selection criteria.

Therefore, the scoping review research synthesis method is warranted for our investigation. Scoping reviews 'serve a different purpose' than systematic reviews [33] and are utilised to examine the presence, extent, variety, and characteristics of the evidence. They are essentially exploratory and are not restricted to a focused research question and specific populations, interventions (exposures) and outcomes [33-35].

This is a protocol of a scoping review with an evidence map. In the absence of available mapping of the volume and content of literature regarding people's experiences regarding AIS, an evidence map study is also warranted [36]. Scoping studies are appropriate at initial stages of evidence mapping to identifying knowledge gaps [33-35]. Both research synthesis methods 'share similarities' with regards to methodology and reporting guidelines [33, 36]. PRISMA-ScR applies both for scoping reviews and for evidence maps [34].

Objectives

We are interested in people's experiences, defined as both 'something that happens to you that affects how you feel' (the *passive* mode) and 'the process of getting knowledge or skill from doing, seeing, or feeling things' (the *active* mode) [37], related to AIS. In terms of Evidence-Based Practice [30-32] our aim is to map the evidence addressing people's experiences in terms of their perspectives, preferences, needs, and values. This scoping review is **not** intended to address the term 'experience' understood as **a component of expertise** of professionals delivering treatment and care, *gained through the years of training and routine*.

The objectives of this scoping review are:

- to map and examine the extent, variety, and nature of the evidence addressing experiences related to AIS
- to explore the depth and the comprehensiveness of current understandings of people's experiences of AIS in everyday life and health and care contexts
- to identify knowledge gaps in this subject matter.

Hence, the main question of the study is: what is known from the available reports about experiences of all those touched by the problem of AIS, both directly and indirectly – taking into consideration both the natural history and the untreated AIS, and the management of this health condition.

METHODS AND ANALYSIS

Protocol design and reporting

We based our protocol on the Joanna Briggs Institute's (JBI) scoping review manual [35] and consulted the PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist and explanation paper [34]. Additionally, we referred to both the original Arksey and O'Malley's scoping review framework [38], and the methodological input from Levac and colleagues [39]. For the reporting of the protocol, we followed the JBI guidance [35], and consulted PRISMA-ScR [34, 40] as well as PRISMA for protocols (PRISMA-P) [41].

Eligibility criteria

We adopted the JBI's Population – Concept – Context (PCC) framework [35] to formulate the objectives and research questions, and also to conceptualise the study and report characteristics in terms of eligibility criteria. The PCC characteristics of our study are elaborated on in Table 1.

Table 1 Objectives and eligibility criteria for the review.

Objectives/ Inclusion criteria	Elaboration
Population/ types of participants: - people with adolescent idiopathic scoliosis (AIS) - their significant others - other people involved	- people diagnosed with AIS, regardless of their age - significant others: e.g. parents, siblings, friends, but also professionals in some cases - people involved in the management of AIS - sources that exclusively focus on other than AIS types of scoliosis (e. g. scoliosis related to other health conditions, early onset scoliosis) will not be considered
Concept/ phenomena of interest: - people's experience related to AIS - size and volume/ depth and breadth/ comprehensiveness of the body of literature regarding people's experience related to AIS	Information sources regarding quality of life, body image, mood, depression, anxiety, mental health, activities of daily living, and other medical and social issues will be considered for inclusion if provide experience-related body of evidence
Context/ setting: - everyday life - health care context	Country and culture: any country, regardless of cultural context (e.g. the issue of school screening is a subject of analyses in countries and cultures worldwide)

Eligible study designs. We will consider any quantitative, qualitative, and mixed-methods primary study designs, including different qualitative research methods like narrative, phenomenology, grounded theory, ethnography and case study, as well as any research synthesis reports. Narrative reviews and opinion pieces, including editorials, letters, debate, commentary, and viewpoint papers, will also be considered. Publications such as essays, diaries, newspaper articles, newsletters, blogs, fiction, will not be considered as eligible. We will provide a list of excluded studies and publications, with reasons for exclusion.

Other limits. Sources in English, Polish, Scandinavian, and German languages will be considered for inclusion. If found relevant (based on abstract, summary, table of contents, heading or introduction), for studies in Russian, French, and Chinese, we will consider inviting colleagues with relevant expertise for collaboration as interpreters. There will be no restriction as to publication date but in the charting process sources will be analysed as relevant to current practice or as historical, based on their publication date, content and context. Commercial information and information provided by sources having potential conflicts of interests (e.g. personal stories published on websites popularising diagnostic or treatment methods) will be excluded. We will not conduct searches of social networks and blogs. We will consider research papers concerning social media use addressing the objectives of our study.

Information sources

Given the subject matter, the characteristics of published relevant narrative reviews [1-3, 5, 7, 19], evidence synthesis reports [13, 14, 19], research recommendations [14, 20, 23], and based on our

preliminary searches, we assume that a search and selection process, including both academic and grey literature sources, is necessary for this study.

When deciding whether to qualify information sources as grey literature, we will follow the widely accepted 'Luxembourg definition' of grey literature as work that 'is produced on all levels of government, academia, business, and industry in print and electronic formats, but which is not controlled by commercial publishers, i.e. where publishing is not the primary activity of the producing body' [42]. We are also informed by the explanation of grey literature complementing the AMSTAR 2 tool for quality appraisal of systematic reviews [43].

Search strategy

We organised our exploratory search process into following stages: (1) academic literature search, (2) grey literature search, (3) complementary hand searches (snowballing searching) of the reference lists of the included publications, and (4) contacting authors.

Electronic bibliographic databases. To achieve satisfactory and required comprehensiveness and completeness of our searches, we need to conduct our searches both in a manner typical for scoliosis review studies – in medically oriented databases, and also in databases covering social sciences. We will search in general bibliographic and research synthesis databases. We will also search in databases provided by academic publishers as, especially for social science publications, we need to conduct searches in particular journals. Databases to be searched include PubMed, MEDLINE (via EBSCO), SportDiscus (via EBSCO), Web of Science including Social Sciences Citation Index, Scopus, ProQuest, PsycINFO, Social Sciences Full Text (EBSCO), JSTOR, GoogleScholar, Cochrane CENTRAL, Joanna Briggs Institute, Campbell Library, Epistemonikos, SpringerLink, ScienceDirect (Elsevier), Wiley Online Library and Taylor & Francis Online. The list may be extended by including other key publishing houses.

Grey literature. We formulated the following grey literature search strategy [43, 44]:

(1) Grey literature databases search: Open Grey, Proquest Dissertations & Thesis Global, New York Academy of Medicine's Grey Literature Report, Google Scholar, Web of Science
(2) The Grey Matters checklist
(3) Google search; we will search the first ten pages for the search hits (i.e. 100 records to be screened for each set of search terms), as a recommended method allowing to capture the most relevant records while maintaining feasibility
(4) Targeted web-based searches: websites of institutions, organisations, and patient groups.

We will conduct the grey literature search, after concluding the academic literature search , so that we will be better acquainted with the search and selection process.

Hand searching of the reference lists of the included publications will be done consecutively throughout the searching process.

Contacting the authors. We will contact key authors known to publish in this area for any additional published or unpublished work.

We will conduct the searches using all identified keywords and index terms. The initial search strategies for PubMed and for grey literature, including a list of selected websites, are presented as Supplementary file 1.

Selection of sources, critical appraisal and data charting

Organisation of the process. The study team consists of two senior researchers, one of them with an expertise in scoliosis studies and in research synthesis methods, and one with expertise in

phenomenology and in qualitative studies. The third author is a doctoral candidate with a background in phenomenology and in qualitative studies.

We will apply the iterative team approach to selecting sources, for data charting from and critical appraisal of the included literature. The screening and study selection, as well as data charting and critical appraisals will be undertaken by one reviewer and two verifiers, working independently. Then the reviewer and the verifiers will resolve discrepancies, if present, by discussion. If needed, we will invite two collaborators to support us with the data charting process.

Selection of sources. We will use two combined flow diagrams for academic and for grey literature search and selection processes, based directly on the PRISMA flowchart [45] and adapted from Godin et al [42], respectively. The results of both searches will be combined, and then, if applicable, supplemented with the results of the hand-searches of the reference lists. We will use a hand-search table for reporting results of hand-searches. The template flow diagrams and a template hand-search table are attached as Supplementary file 2.

Data charting framework. We will use a data charting table for the process of data charting from the included sources. Our aim is to use the form at the review stage, and we assume that the data charting process is iterative so that the charting table might be updated during the review process. The data charting form is attached as Supplementary file 3.

Methodological quality appraisal.

During the data charting process, we will additionally assess methodological quality of the included literature. We will use the Mixed Methods Appraisal Tool (MMAT), version 2018 [46], which is designed to appraise the methodological quality of empirical studies – qualitative research, randomized controlled trials, non-randomized studies, quantitative descriptive studies, and mixed methods studies, as well as the Joanna Briggs Institute Checklist for Text and Opinion [47] for theoretical or opinion publications. For systematic reviews of randomised or non-randomised studies of interventions, we will apply the AMSTAR 2 [43] tool.

Calibration exercises. We will conduct pilot tests (calibration exercises) to ensure systematic and reproducible study selection, and to confirm satisfactory interrater agreements, as well as to familiarise the review team with the data charting form and to test the comprehensiveness of its content. The data charting form will be trialled on two reports [7, 12].

Characteristics of the included sources of evidence. We will present characteristics for which data were charted and will provide the citations for each source of evidence in an evidence summary table [34-36], corresponding to the data charting table. It will be presented in the final report to map the evidence regarding the objectives of this scoping review.

Protocol registration. We made our protocol publicly visible via the Open Science Framework (OSF) website (https://osf.io/3yr76/, created 07 02 2019).

Changes to the protocol. Giving the exploratory characteristics of the study, we can expect amendments to the search and selection process, and, consequently, to the data charting table during the review process. If done, this will be reported through the OSF registry and in the final report.

Key dates. We made our first attempts to this scoping review starting in November 2018, and conducted initial exploratory searches in February 2019. We expect to start the actual study in November 2019 and to prepare the report by July 2020.

Patient and public involvement. There was no patient or public involvement in the creation of this protocol and is not planned in the review, in accordance with the objectives of this study.

DISCUSSION

The management of AIS needs to be considered, in terms of person-centred aspects of care, including people's experiences and everyday life beyond health professional settings. This scoping review is intended to supplement the body of evidence with a research synthesis report regarding people's experiences regarding AIS. Implementation of the wide and exploratory scoping review research synthesis method, rather than a systematic review approach, is ideal for that purpose.

The exploratory and open characteristics of the scoping review approach, both as regards methodology, and the subject matter of this study, allows us to conduct the review in an iterative, evolving way. Nonetheless, we faced some important issues at the stage of creating the protocol.

Conduct guidelines considerations. We chose the current JBI guidance [35] for scoping review conduct, as it is consistent with the PRISMA-ScR guidance [34], and it addresses, utilises, and improves earlier scoping review methodology proposals [36, 38, 39]. More importantly, the JBI model of Evidence-Based Health Care [32] corresponds with the concept of our study, with the principles of the evidence for feasibility, appropriateness, meaningfulness of interventions for specific populations, cultures and contexts, as being of equal value to the evidence of effectiveness. This model acknowledges the broad conceptualisation of evidence, with the pronunciation of varying sources of evidence.

Reporting guidelines considerations. We will follow the PRISMA-ScR reporting guidelines in the final report of the scoping review. As to the protocol reporting, PRISMA-P is the standard reporting guideline for systematic review protocols [41], while the only general guidance for the content of scoping review protocols is provided in the JBI manual [35]. Therefore, in order to specify the most accurate checklist and content of our protocol, we conducted a comparative exercise of the PRISMA-ScR (in two slightly differing versions [34, 40]) and the corresponding items of the PRISMA-P.

Application of results

This scoping review is intended to identify existing practice and research gaps to inform researchers, but also all those involved in the management and care of people diagnosed with AIS, including practitioners, policy makers, and interest groups and organisations in the field. Especially, this scoping review can inform developers of recommendations and practice guidelines.

Strengths and limitations considerations

Methodological quality, risk of bias and strength of evidence. Our goal is to map the available publications, with minimal restrictions as to study designs, and with a wide grey literature search, in order to identify evidence gaps and research needs. Critical appraisal of the methodological quality or risk of bias within the individual sources of evidence is not expected for scoping reviews [33, 34, 38] Nonetheless, to strengthen the trustworthiness of our study, we will conduct a critical appraisal of the included individual publications. We are not going to conduct any syntheses of results or any assessment of the overall strength of the body of evidence.

Social media and blogs as sources of evidence. Despite potential large body of knowledge attainable from those sources, taking into account methodology guidance for scoping studies [35, 36, 38, 39], and probable difficulties in meaningful and sound analyses of such texts [48, 49], we assumed that including social media analyses is inapplicable within this review. A separate study is probably required for that task.

The **planned recipients** of the included sources of evidence (e.g. be it a peer-reviewed journal report produced as a scientific activity or a solicited report for a stakeholder, such as agency or a committee, or other policy maker), as well as study author affiliations (e.g. whether the authors are independent or connected to a scoliosis treatment clinic or to a spinal deformity scientific organisation or a group of professionals), are potential important factors in relation to the characteristics of the included sources of evidence, and their trustworthiness. We will describe those characteristics, as well as sources of funding for the included sources of evidence, in a text and in a separate table.

Evidence mapping. The graphical representation of evidence mapping in the final report will be done as tabular qualitative summaries and flow diagrams of the searching and selection processes, as well as tables containing characteristics of hand search results and characteristics of relevant websites and online materials, but not bubble plots. This is consistent with the characteristics and requirements for evidence maps [36].

Consultations. The optional, sixth stage of the scoping review framework (*Stage 6: Consultation*), as originally proposed by Arksey and O'Malley [38], involves consultations with key stakeholders in order to broaden the literature searching and selection process (i.e. to include further sources of knowledge indicated by the stakeholders) and to receive their feedback as to the findings of the scoping review. Our scoping review is, however, not intended to involve consultation with stakeholders for translating knowledge at this stage of the study. Our aim is to examine and to synthesise the body of literature, and to distribute the findings. The implementation and dissemination stage is too distant at this point.

Ethic and dissemination

Scoping review is a type of a research synthesis, secondary study, aiming at synthesising data from publicly available publications, hence it does not require ethical approval.

The report of this scoping review will be submitted to a peer-reviewed journal. A dissemination of the findings among professionals involved in scoliosis management and policymaking is also planned.

Author Contributions. MP contributed with the idea of the review and proposed the design of the work. MP, EJ and WG conceptualized the study and MP and WG implemented the scoping review frameworks. MP drafted and edited the manuscript and the supplementary material, and EJ and WG revised it critically and contributed for its final version. All authors read and approved the final version of the manuscript.

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Competing interests. None declared.

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Supplementary file 1. Initial search strategy.

1. Academic literature search:

PubMed search strategy:

((((("scoliosis"[MeSH Terms] OR "scoliosis"[All Fields]) OR ("Spine Deform"[Journal] OR ("spine"[All Fields] AND "deformity"[All Fields]) OR "spine deformity"[All Fields]) OR (spinal[All Fields] AND ("congenital abnormalities"[MeSH Terms] OR ("congenital"[All Fields] AND "abnormalities"[All Fields]) OR "congenital abnormalities"[All Fields] OR "deformity"[All Fields])))) AND (("persons"[MeSH Terms] OR "persons"[All Fields] OR "person"[All Fields]) OR ("persons"[MeSH Terms] OR "persons"[All Fields] OR "people"[All Fields]) OR ("parents"[MeSH Terms] OR "parents"[All Fields] OR "parent"[All Fields]) OR peer[All Fields] OR ("family"[MeSH Terms] OR "family"[All Fields])))) AND (experiences[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "opinions"[All Fields]) OR views[All Fields] OR ("attitude"[MeSH Terms] OR "attitude"[All Fields] OR "attitudes"[All Fields]) OR acceptance[All Fields] OR ("affect"[MeSH Terms] OR "affect"[All Fields] OR "mood"[All Fields]) OR ("depressive disorder"[MeSH Terms] OR ("depressive"[All Fields] AND "disorder"[All Fields]) OR "depressive disorder"[All Fields] OR "depression"[All Fields] OR "depression"[MeSH Terms]) OR ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields]) OR ("self concept"[MeSH Terms] OR ("self"[All Fields] AND "concept"[All Fields]) OR "self concept"[All Fields] OR ("self"[All Fields] AND "image"[All Fields]) OR "self image"[All Fields]) OR (("ego"[MeSH Terms] OR "ego"[All Fields] OR "self"[All Fields]) AND acceptance[All Fields]) OR ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields]) OR ("motor activity"[MeSH Terms] OR ("motor"[All Fields] AND "activity"[All Fields]) OR "motor activity"[All Fields] OR "activity"[All Fields]) OR participation[All Fields])) AND idiopathic[All Fields]

2. Grey literature:

1. Targeted web-based searches (a template table with initial websites):

Website name/ organisation	link
Scoliosis Research Society, SRS	https://www.srs.org/
Society on Scoliosis Orthopaedic and Rehabilitation Treatment	http://sosort.mobi/index.php/en/
International Research Society for Spinal Deformities, IRSSD	https://www.irssd.org/
Physical and Rehabilitation Medicine Section and Board of the European Union of Medical Specialists	https://www.euro-prm.org/index.php?lang=en
UK National Screening Commitee	https://www.gov.uk/government/groups/uk-national-screening-committee-uk-nsc
British Scoliosis Society	http://www.britscoliosissoc.org.uk/
British Scoliosis Research Foundation	http://www.bsrf.co.uk/
Scoliosis Priority Setting Partnership	http://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/
Scoliosis Australia	https://www.scoliosis-australia.org/
Spine Society of Australia	http://www.spinesociety.org.au/
Scoliosis Association of Australia	https://www.badbacks.com.au/info/links/back-care-

Website name/ organisation	link
	health-australia-new-zealand/scoliosis-association-of-australia
American Association of Neurological Surgeons, AANS	https://www.aans.org/Patients/Neurosurgical-Conditions-and-Treatments/Scoliosis
Pediatric Orthopedic Society of North America, POSNA	https://posna.org/
National Scoliosis Foundation	www.scoliosis.org
Scoliosis Association	https://www.sauk.org.uk/
Setting Scoliosis Straight Foundation	http://www.settingscoliosisstraight.org/
Familydoctor.org (American Academy of Family Physicians)	https://familydoctor.org/condition/scoliosis/
Choosing Wisely (American Academy of Family Physicians)	https://www.aafp.org/about/initiatives/choosing-wisely.html
Healio	https://www.healio.com/pediatrics
MedlinePlus	
UpToDate	https://www.uptodate.com/contents/adolescent-idiopathic-scoliosis-clinical-features-evaluation-and-diagnosis
PracticeUpdate	https://www.practiceupdate.com/explore/

2. Google search engine:

Date searched:
Searches “All results” – first 10 pages, representing 1000 results screened:

#	search	# new potentially relevant records	# new full records analysed	total # new records
1	scoliosis AND experience			
2	scoliosis OR spine AND experience			
3	scoliosis AND story OR narrative OR narratives			
4	scoliosis OR spine AND story OR narrative OR narratives			
5	scoliosis AND opinion			
6	scoliosis OR spine AND opinion			
7	scoliosis AND quality of life			
8	scoliosis OR spine AND quality of life			
9	scoliosis AND perspective			
10	scoliosis OR spine AND perspective			
11	scoliosis AND activity OR participation			
12	scoliosis OR spine AND activity OR participation			

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Supplementary file 2. Selection of sources flow charts.

Figure S2a. Flow chart step 1 template for the selection of sources of evidence from academic sources.

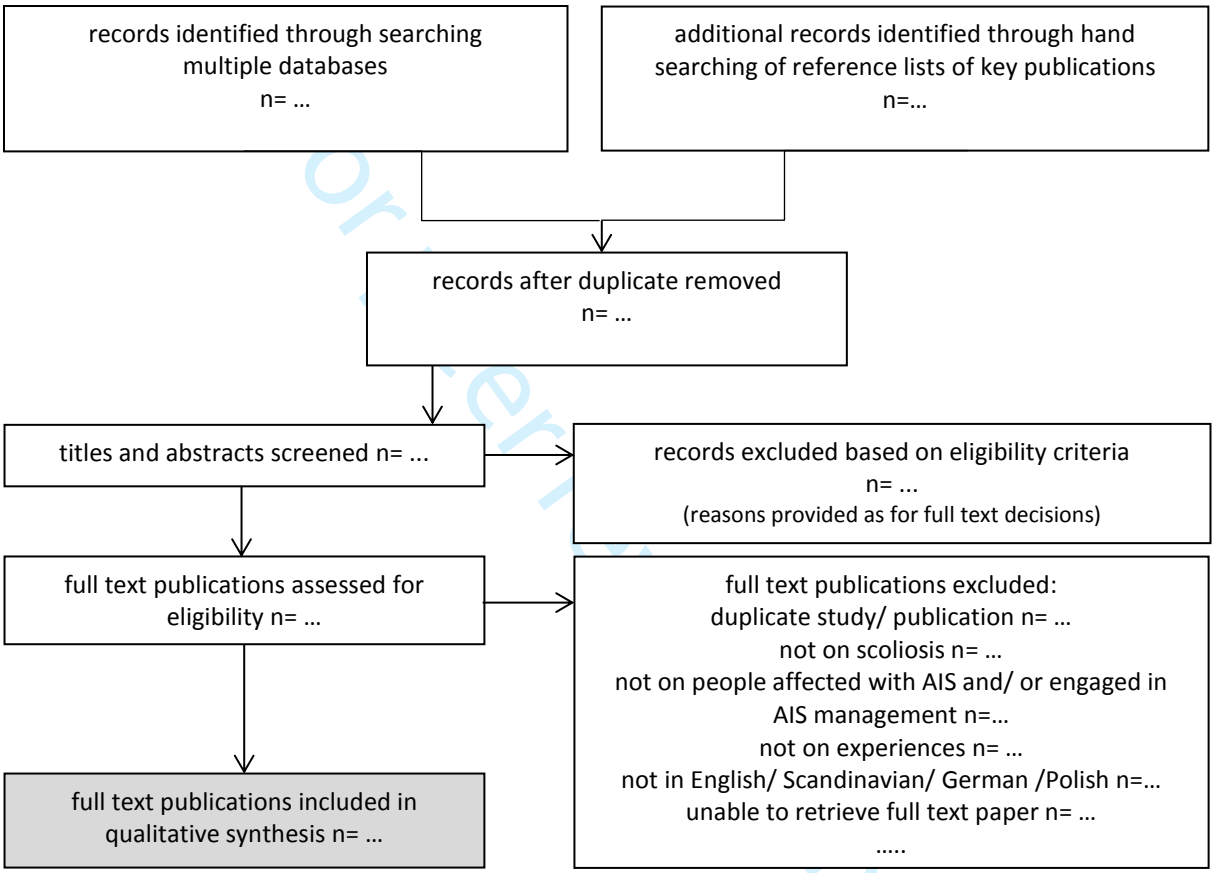

Figure S2b. Flow chart step 2 template for the selection of sources of evidence from grey literature. Adapted from Godin et al [syst rev 2015…], modified.

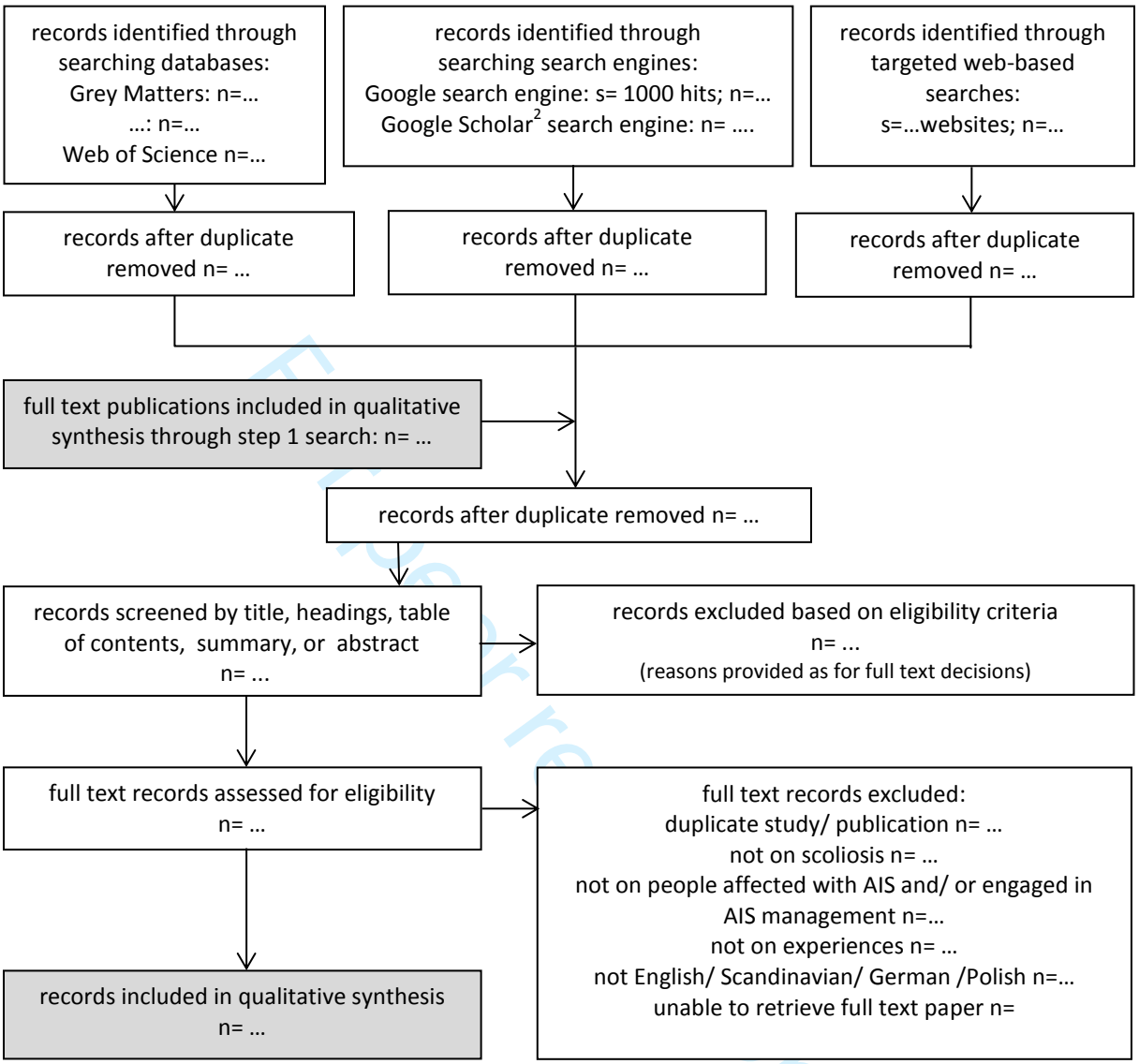

Table S2. Step 3 Hand search of the reference lists of key publications.

key publications included for reference list searching	reference screened for eligibility	decision	
		include	exclude, with reason
..			
..			

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Supplementary file 3. Data charting form.

Study Details and Characteristics:											
Citation:											
publication type:	academic:		grey:		unpublished:						
Type of study	primary:		secondary:		tertiary:		other:				
Study design:											
Origin/ country of origin: (where the study was conducted)											
Content:											
Aims/ objectives of the study:											
AIS as the problem:		Health conditions related to AIS as the problem:									
Diagnostics as the problem:		Screening as the problem:									
Treatment as the problem:		Other people as the problem:									
Cosmetics / appearance as the problem:		Other (e.g. physical activity/ sports/ lifestyle):									
Research questions (if applicable):											
Eligibility criteria:											
What is reported (e.g. views, opinions, experiences):											
How 'experience' is used (definition / understanding)											
Context:											
Country/ region/ state:											
Culture and societal aspects (e.g. education, religion, beliefs, norms):											
Setting (e.g. school, outpatient clinic, community/ home):											
Basis for the programme/ intervention/ treatment (national/ regional guidelines, statements, recommendations, individual programme, other):											
Scoliosis in the family:											
Other:											
Participants:											
affected person(s) ☐ relative(s) ☐ other person(s) (who):											
Age:		Number:									
Sex:		severity of AIS:									
Data on progression:											
Treated ☐		Untreated ☐									
Other characteristics (e.g. related to relatives/ other people, e.g. scoliosis in the family)											
Details/Results/ outcomes extracted from study (in relation to the **concept** of the scoping review):											
How diagnosed:											
Screening ☐	Visit ☐	Other (e.g. physiotherapist, leaflet used by parents):									
Diagnostic imaging:	YES / NO	Details, if YES (e.g. device, dose, no of exposures, area):									

Type of treatment(s)/ intervention(s) □	experiences related to untreated persons □
Length (and sequence, if applicable) of treatment(s):	
Primary (person-centred) outcomes:	
Related to effectiveness (e.g. hopes and expectations):	
Related to harms (e.g. stigma, labellisation, pain, discomfort, x-ray exposure):	
Related to time, daily routine, time management and finance:	
Other:	
Secondary outcomes (any related to the treatment process, as in biomedical literature):	
Effectiveness of intervention(s) (e.g. Cobb angle, progression):	
Harms (biomedical, e.g. x-ray exposure):	
Other:	
Additional information / notes:	
key findings that relate to the scoping review questions:	
gaps in the research/ practice:	

Date:

Reviewer: