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Application of diagnostic criteria in pediatric complex regional pain syndrome: A scoping review protocol

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Complete List of Authors:	Tham, See Wan; University of Washington School of Medicine, Department of Anesthesiology and Pain Medicine; Seattle Children's Research Institute, Center for Child Health, Behavior and Development Lee, Rebecca; The University of Manchester Faculty of Biology Medicine and Health, Center for Epidemiology, Center for Musculoskeletal Research, Division of Musculoskeletal and Dermatological Sciences; Manchester University NHS Foundation Trust, National Institute for Health Research Biomedical Research Center; The University of Manchester, Manchester Centre for Health Psychology, Division of Psychology and Mental Health Rau, Lisa-Marie; Children's & Adolescents' Hospital Datteln, German Paediatric Pain Centre; Witten/Herdecke University, Department of Children's Pain Therapy and Paediatric Palliative Care, Faculty of Health, School of Medicine Sethna, Navil; Boston Children's Hospital, Anesthesiology, Critical Care and Pain Medicine, Harvard Medical School Nylander, Elisabeth; Seattle Children's Hospital, Library and Information Commons, Seattle Children's Research Center Fabrizi, Lorenzo; University College London, Department of Neuroscience, Physiology and Pharmacology, Division of Biosciences Wager, Julia; Children's and Adolescents' Hospital Datteln, German Paediatric Pain Centre; Universitat Witten/Herdecke, Department of Children's Pain Therapy and Paediatric Palliative Care, Faculty of Health, School of Medicine	
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- 3 4	Application of diagnostic criteria in pediatric complex regional pain syndrome: A scoping
5 6	review protocol
7 8 9	Authors: See Wan Tham MBBS ^{a,b} , Rebecca R. Lee ^{c,d,e} , Lisa-Marie Rau, M.Sc. ^{f,g} , Navil
10 11 12	Sethna, MD ^h , Elisabeth M. Nylander, MSc ⁱ , Lorenzo Fabrizi ^j , Julia Wager, PhD ^{f,g} , Helen
13 14	Koechlin PhD ^{k,I,m}
15	Affiliation:
17	^a Department of Anesthesiology and Pain Medicine, University of Washington School of
18	Medicine, Seattle, WA, United States
19 20	^b Center for Child Health, Behavior and Development, Seattle Children's Research Institute.
21	Seattle WA United States
22 23	^c Centre for Enidemiology Centre for Musculoskeletal Research. Division of Musculoskeletal and
24	Dermatological Sciences, Eaculty of Biology, Medicine and Health, University of Manchester
25 26	Manahastar Academia Haalth Science Contro. Manahastar LIK
27	d National Institute for Uselle Desearch Disputies Desearch Contra Manchester Usiversity
28 29	
30	Hospital NHS Trust, Manchester, UK.
31 32	^e Manchester Centre for Health Psychology, Division of Psychology and Mental Health,
33	University of Manchester, Manchester, UK.
34 35	^f German Paediatric Pain Centre, Children's and Adolescents' Hospital Datteln, Datteln,
36	Germany
37 38	^g Department of Children's Pain Therapy and Paediatric Palliative Care, Witten/Herdecke
39	University, Faculty of Health, School of Medicine, Witten, Germany
40 41	^h Department of Anesthesiology, Critical Care and Pain Medicine, Boston Children's Hospital,
42	Harvard Medical School, Boston, Massachusetts, USA.
43 44	ⁱ Library and Information Commons, Seattle Children's Hospital and Research Institute, Seattle,
45	WA. United States
46 47	Department of Neuroscience, Physiology and Pharmacology, Division of Biosciences
48	University College London London LIK
49 50	^k Department of Payabasamatics and Payabistry University Children's Heapital University of
51	
52 53	Zurich, Zurich, Switzerland
54	Division of Child and Adolescent Health Psychology, Department of Psychology, University of
55 56	Zurich, Zurich, Switzerland
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1	
2	
3 1	^m Children's Research Centre, Universit
5	Switzerland
6 7	Corresponding Author:
8	See Wan Tham, MBBS
9 10	M/S Cure-3 PO Box 5371
11	
12	Seattle, WA 98145-5005,
13	United States
14	E-mail: see.tham@seattlechildrens.org
16	Tel: 1 206 88/1278
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Abstract

Introduction There are no validated pediatric specific diagnostic criteria for complex regional pain syndrome (CRPS). As a result, diagnostic tools developed for adults (e.g., Budapest Criteria, Japanese Diagnostic Criteria, Veldman criteria) are frequently applied in the pediatric population. However, the clinical presentations and trajectories of children can differ from adults. Given that treatment outcomes are linked to early diagnosis and intervention, the lack of pediatric specific screening or diagnostic tools is an important knowledge gap. We aim to identify the frequency of individual criteria used in diagnosing CRPS in children and adolescents in existing literature, summarize assessment methods used to establish the diagnosis, and provide recommendations for research and clinical application.

Methods The following databases and platforms will be searched for articles published from 2003 (year the Budapest Criteria was developed) onward: CINAHL, CENTRAL, Embase, Ovid MEDLINE, PubMed, PsycINFO, and Web of Science. Our search strategy will use subject headings and text words related to the concepts of CRPS in pediatric populations, with study inclusion criteria from birth up to 18 years old, and a diagnosis of CRPS. Data will be extracted by our multidisciplinary team and findings will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews. Ethics and dissemination This study does not involve human participants or unpublished data, therefore approval from a human research ethics committee is not required. The findings of this scoping review will be disseminated through academic conferences and peer-reviewed publications.

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- Strengths and limitations of this study
- This scoping review will systematically identify the frequency of criteria used in diagnosing pediatric CRPS, thereby addressing an important gap in the literature.
- Through an analysis of applied diagnostic criteria, this scoping review will provide suggestions for pediatric specifications for CRPS and recommendations for clinical practice and implementation.
- Findings on the frequency of diagnostic criteria for CRPS in children and adolescents are • expected to be heterogeneous. However, this will provide a foundation for developing a o stance. systematic approach to standardize diagnosis and facilitate further psychometric evaluation.

Introduction

Complex regional pain syndrome (CRPS) is a chronic pain condition that presents with severe pain, affecting the distal extremities (1). This is accompanied by altered sensory perception such as hyperalgesia and/or allodynia, vasomotor, trophic and autonomic dysfunction (2,3). There may be an inciting event (e.g., trauma), however, no causes may be identified in pediatric populations (4). The clinical presentation of debilitating pain, skin discoloration, temperature changes, swelling, and hyperhidrosis of the affected region is highly distressing for children and adolescents, leading to significant pain-related disability (5). The incidence of pediatric CRPS is estimated to be 1.14/100,000 children per year (6). The underlying pathophysiology remains poorly understood, and it is hypothesized that dysfunction within the somatosensory system, combined with a complex interplay of biopsychosocial risk factors contributes to its manifestation (7–10).

There are challenges in formulating the diagnosis of CRPS, as there are no confirmatory objective test(s) or biological markers. In adults, validated diagnostic criteria have been developed, such as the Budapest Criteria (11), which was formally adopted by the International Association for the Study of Pain (IASP) in 2003 following a consensus conference in Budapest. Those criteria have since been identified as the gold standard for diagnosis of CRPS in adults (4). Unfortunately, research remains nascent on the development and validation of diagnostic criteria in pediatric populations. Given this limitation, adult diagnostic criteria have been applied clinically and in research studies for children (12). However, based on age and developmental stage, the transferability is questionable as clinical characteristics, symptom trajectory and response to treatment in children differ from adults (6,13,14). For example, involvement of the lower extremities is more common in children, and trophic changes are similarly uncommon (13). Furthermore, studies also suggest that symptoms in children are milder, and the longitudinal trajectory seems more favorable compared to adults (11). Recognizing that the developmental, neurocognitive and behavioral differences can also impact clinical presentation

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and evaluation, the direct application of adult diagnostic criteria for children may inadvertently result in delayed or inaccurate diagnoses and inappropriate care. As treatment outcomes (e.g., physical functioning, pain severity) have been linked to early diagnosis and intervention (13), the lack of pediatric-specific screening or diagnostic tools for CRPS is a significant research and knowledge gap.

Given the lack of pediatric specific diagnostic tool, the Budapest Criteria is commonly used to diagnose CRPS in pediatric populations (15,16). However, in findings from a systematic review on pediatric CRPS, the majority of studies (> 50%) used authors' own criteria and/or assigned the diagnosis based upon clinician expertise, further highlighting this research gap in diagnostic consistency (15). More recently, research has advanced in the work by Mesaroli and colleagues, who developed a pediatric screening tool, the Pediatric PainSCAN. Preliminary validation efforts focused on establishing content validity for pediatric CRPS and neuropathic pain (17). This measure has yet to undergo additional psychometric testing, limiting its application to date.

Besides formulating pediatric specific criteria, methods of clinical assessment for identifying each criterion within the diagnostic tool should be considered (18). The process of obtaining a history and physical examination to evaluated for presence of clinical features can differ dramatically between children and adults, as would be expected given the age-related developmental, cognitive, behavioral and communication considerations. Moreover, children's neurological and physiological development undergo constant changes across the pediatric lifespan, lending to potential differences within the pediatric age groups (19). A pediatric focused tool should incorporate these multidimensional factors in order to address these differences.

Taken together, there is a need to identify the diagnostic criteria used for diagnosing CRPS in pediatric populations and to systematically characterize the criteria that have been used in previous studies, including authors' own criteria and clinician assessments. Therefore, the objectives of this scoping review are to identify the frequency of individual criteria used in

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diagnosing CRPS in children and summarize the assessment methods used to establish the diagnosis. Finally, we will also recommend optimizing these diagnostic criteria for use in clinical practice and research.

Methods and analysis

This proposed scoping review is reported in accordance with the PRISMA-ScR guidelines.

Eligibility criteria

Participants

We are interested in studies on participants ages birth up to 18 years old, with a clinical diagnosis of CRPS. Studies should include any type of established diagnostic criteria (e.g., Budapest Criteria, Veldman Criteria) and those as defined by authors (e.g., symptoms, signs). If studies include samples that span a larger age range into early adulthood, e.g., 14 - 21 years, they can be included, when either, the mean age is below 18 years, with a maximum age of < 24 years, as previously recommended for pediatric pain research (20), or outcomes are reported separately for patients ≤18 years.

Types of evidence sources

This scoping review will include published peer-reviewed full text articles written in English, presenting original data with retrospective or prospective study designs, including case reports, case series, case-control, cross-sectional, time-series, longitudinal cohort, and randomized-controlled trials studies. Commentaries may be included if the inclusion criteria are met and original data are presented. The following types of articles will be excluded: reviews (e.g., narrative, scoping, systematic), meta-analyses, clinical trial registrations, letters to the editor, opinion articles, essays, dissertations, conference abstracts, posters, books, book reviews, and book chapters.

Search Strategy

Before undertaking this review, the PROSPERO database was searched for ongoing or recently completed systematic reviews and/or meta-analyses on the same topic. A research librarian

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(EN) with expertise in evidence synthesis will develop search strategies to reflect the concepts outlined in Table 1 below. A PubMed search strategy was developed with input from the project team, and then peer reviewed by a second librarian, not otherwise associated with the project. The intended PubMed search strategy is included below (Appendix 1). This search strategy will be adapted to the syntax of the other databases/platforms, using search words for the title and abstract fields and controlled vocabulary whenever possible.

The following databases/platforms will be searched: APA PsycINFO (EBSCOHost), CINAHL (EBSCOHost), Cochrane Central Register of Controlled Trials (Wiley), Embase.com, Ovid MEDLINE, PubMed (PubMed-Not-Medline and PubMed In-Process), and Web of Science (WOS, MEDLINE, SCIELO). Searches will be limited to human studies and published from 2003 onward, because the most established CPRS criteria, the Budapest Criteria, were introduced at this time. As relevant studies are identified, we will check for additional relevant cited and citing articles.

Data management and study selection

Search results will be exported into Covidence, a web-based software by Cochrane to assist with the production of reviews (https://www.covidence.org), to enable the identification and removal of duplicates. Study selection will be based on the previously described inclusion/exclusion criteria. For each record, two team members will independently perform the screening process on the title/abstract level as well as the full text assessment. Any disagreements during the screening process will be resolved by a third reviewer, and, if necessary, through discussions in the research team.

Data extraction plan

A customized, standardized extraction form will be used, and data will be organized in a customized extraction form specifically structured for this scoping review. We will extract information on authors, year of publication, countries of study conduct, study aims, study design, sample size, measures for diagnosis of CRPS, individual diagnostic criteria for CRPS,

additional symptoms and signs related to CRPS but not part of diagnostic criteria defined in measures, assessment procedures (e.g. history vs. examination; type of procedure; specific instructions on the evaluation process and interpretations rules), measures assessing psychosocial functioning (e.g., of anxiety, depression, posttraumatic stress disorder, critical life events). Reviewers will be trained on using the data extraction form, and we will pilot the data extraction form on a sample of studies to ensure a common understanding amongst the reviewers Next, independent data extraction of 5 randomly selected publications will be conducted by at two reviewers, followed by discussion of disagreements amongst the entire team. After reaching agreement, subsequent data extraction for each study will be conducted by one team member. The reliability of extraction will be reviewed by a second team member throughout the extraction process, through regular checks to validate the extracted data.

Data synthesis

A search decision flow chart will present the number of studies identified, excluded, and included in accordance with the PRISMA-ScR guidance. Data will be summarized and analyzed descriptively, and study characteristics will be presented in tabulated format. We will determine the frequency of using measures for diagnosis of CRPS, individual diagnostic criteria for CRPS, additional symptoms and signs related to CRPS (but not part of diagnostic criteria), and the inclusion of measures that assessed psychosocial functioning. Based on this quantification, we will present the most prominent signs/symptoms across diagnostic tools/criteria.

Ethics and dissemination

This study does not involve human participants or unpublished secondary data. Approval from a human research ethics committee is not required. The results of this scoping review will be disseminated through peer-reviewed publications, academic conferences and professional societies.

While patients and the public were not directly involved in the initial development of the scoping review protocol design, we plan to engage relevant patient representatives (e.g., children,

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caretakers) and advocacy groups (e.g., International Association for the Study of Pain, Complex Regional Pain Syndrome Special Interest Group) during the interpretation of results and dissemination phase. Future engagement strategies may include co-produced dissemination materials to ensure that the outcomes of this review are meaningful and applicable to the medical and patient communities.

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Table 1. Concepts and key terms for search blocks

MeSH	"pediatrics"[MeSH]	"complex regional pain syndromes"[MeSH]
	"infant"[MeSH]	
	"child"[MeSH]	
	"child, hospitalized"[MeSH]	
	"adolescent"[MeSH]	
	"adolescent hospitalized"[MeSH]	
	"minors"[MeSH]	
	"young adult"[MeSH]	
synonyms	pediatric*	algodystrophic syndrome
	adolescent	algodystrophy
	boy	algoneurodystrophy
	child	causalgia
	girl	chronic regional pain syndrome
	juvenile	complex regional pain syndrome
	kid	CRPS
	minor	Morbus Sudeck
	pubescent	post-traumatic dystrophy
	preadolescence	reflex sympathetic dystrophy
	teen	sympathetic dystrophy
	young adult	sympathetic reflex dystrophy
	youth	Sudeck's atrophy/disease/syndrome
		Sudeck Leriche syndrome
		type 1 regional pain syndrome

Plural forms and alternate spellings will be included, for example, pediatric and pediatrics.

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Study idea conception: SWT, RL, LR, NS, LF, JW, HK
Study design: SWT, RL, LR, NS, LF, EN, JW, HK
Writing of the protocol: SWT, RL, LR, NS, LF, EN, JW, HK
Approval of the final version: SWT, RL, LR, NS, LF, EN, JW, HK
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Appendix 1

Example PubMed search strategy

("pediatrics"[MeSH Terms] OR "child"[MeSH Terms] OR "child. hospitalized"[MeSH Terms] OR "adolescent"[MeSH Terms] OR "adolescent, hospitalized"[MeSH Terms] OR "minors"[MeSH Terms] OR "young adult"[MeSH Terms] OR "paediatric*"[Title/Abstract] OR "pediatric*"[Title/Abstract] OR "adolescen*"[Title/Abstract] OR "boy"[Title/Abstract] OR "boys*"[Title/Abstract] OR "child*"[Title/Abstract] OR "children*"[Title/Abstract] OR "girl*"[Title/Abstract] OR "juvenile*"[Title/Abstract] OR "kid"[Title/Abstract] OR "kids*"[Title/Abstract] OR "minor*"[Title/Abstract] OR "minors*"[Title/Abstract] OR "pre adolescen*"[Title/Abstract] OR "preadolescen*"[Title/Abstract] OR "preteen*"[Title/Abstract] OR "pubescen*"[Title/Abstract] OR "teen*"[Title/Abstract] OR "teenage*"[Title/Abstract] OR "young adult*"[Title/Abstract] OR "young individual*"[Title/Abstract] OR "young man"[Title/Abstract] OR "young men"[Title/Abstract] OR "young person*"[Title/Abstract] OR "young people*"[Title/Abstract] OR "young woman*"[Title/Abstract] OR "young women*"[Title/Abstract] OR "youngster*"[Title/Abstract] OR "youth*"[Title/Abstract]) AND ("complex regional pain syndromes"[MeSH Terms] OR "algodystroph*"[Title/Abstract] OR "algoneurodystroph*"[Title/Abstract] OR "causalgia*"[Title/Abstract] OR "chronic regional pain syndrome*"[Title/Abstract] OR "complex regional pain syndrome*"[Title/Abstract] OR "crps*"[Title/Abstract] OR "morbus sudeck"[Title/Abstract] OR "post traumatic dystroph*"[Title/Abstract] OR "posttraumatic dystroph*"[Title/Abstract] OR "reflex sympathetic dystroph*"[Title/Abstract] OR "sudeck* atroph*"[Title/Abstract] OR "sudeck* disease"[Title/Abstract] OR "sudeck* dystroph*"[Title/Abstract] OR "sudeck leriche syndrome*"[Title/Abstract] OR "sudeck* syndrome*"[Title/Abstract] OR "sympathetic dystroph*"[Title/Abstract] OR "sympathetic reflex dystroph*"[Title/Abstract]) AND 2003/01/01:2024/12/31[Date - Publication] AND "english"[Language]

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Complete List of Authors:	Tham, See Wan; University of Washington School of Medicine, Department of Anesthesiology and Pain Medicine; Seattle Children's Research Institute, Center for Child Health, Behavior and Development Lee, Rebecca; The University of Manchester Faculty of Biology Medicine and Health, Center for Epidemiology, Center for Musculoskeletal Research, Division of Musculoskeletal and Dermatological Sciences; Manchester University NHS Foundation Trust, National Institute for Health Research Biomedical Research Center; The University of Manchester, Manchester Centre for Health Psychology, Division of Psychology and Mental Health Rau, Lisa-Marie; Children's & Adolescents' Hospital Datteln, German Paediatric Pain Centre; Witten/Herdecke University, Department of Children's Pain Therapy and Paediatric Palliative Care, Faculty of Health, School of Medicine Sethna, Navil; Boston Children's Hospital, Anesthesiology, Critical Care and Pain Medicine, Harvard Medical School Nylander, Elisabeth; Seattle Children's Hospital, Library and Information Commons, Seattle Children's Research Center Fabrizi, Lorenzo; University College London, Department of Neuroscience, Physiology and Pharmacology, Division of Biosciences Wager, Julia; Children's and Adolescents' Hospital Datteln, German Paediatric Pain Therapy and Paediatric Palliative Care, Faculty of Health, School of Medicine	
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Secondary Subject Heading:	Evidence based practice	
Keywords:	Child, Adolescent, Chronic Pain	

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Application of diagnostic criteria in pediatric complex regional pain syndrome: A scoping review protocol

Authors: See Wan Tham MBBS ^{a,b}, Rebecca R. Lee ^{c,d,e}, Lisa-Marie Rau, MSc ^{f,g}, Navil

Sethna, MD^h, Elisabeth M. Nylander, MScⁱ, Lorenzo Fabrizi^j, Julia Wager, PhD^{fg},

Helen Koechlin PhD k,l,m

Affiliation:

^aDepartment of Anesthesiology and Pain Medicine, University of Washington School of Medicine, Seattle, WA, United States ^bCenter for Child Health, Behavior and Development, Seattle Children's Research Institute, Seattle, WA, United States °Centre for Epidemiology, Centre for Musculoskeletal Research, Division of Musculoskeletal and Dermatological Sciences, Faculty of Biology, Medicine and Health, University of Manchester, Manchester Academic Health Science Centre, Manchester, UK. ^d National Institute for Health Research Biomedical Research Centre, Manchester University Hospital NHS Trust, Manchester, UK. ^e Manchester Centre for Health Psychology, Division of Psychology and Mental Health, University of Manchester, Manchester, UK. ^f German Paediatric Pain Centre, Children's and Adolescents' Hospital Datteln, Datteln, Germany ⁹ Department of Children's Pain Therapy and Paediatric Palliative Care, Witten/Herdecke University, Faculty of Health, School of Medicine, Witten, Germany ^hDepartment of Anesthesiology, Critical Care and Pain Medicine, Boston Children's Hospital, Harvard Medical School, Boston, Massachusetts, USA. Library and Information Commons, Seattle Children's Hospital and Research Institute, Seattle, WA, United States Department of Neuroscience, Physiology and Pharmacology, Division of Biosciences, University College London, London, UK ^kDepartment of Psychosomatics and Psychiatry, University Children's Hospital, University of Zurich, Zurich, Switzerland

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1 2 3 4	^D ivision of Child and Adolescent Health Psychology, Department of Psychology, University of
5	Zurich, Zurich, Switzerland
7	^m Children's Research Centre, University Children's Hospital Zurich, University of Zurich, Zurich,
8	Switzerland
9 10	Corresponding Author:
11	See Wan Tham MBBS
12	M/S Cure-3 PO Box 5371
14	Soottlo WA 08145 5005
15 16	Seallie, WA 90143-5005,
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18 19	E-mail: <u>see.tham@seattlechildrens.org</u>
20	<u>Tel: 1 206 8841278</u>
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Abstract

Introduction There are no validated pediatric specific diagnostic criteria for complex regional pain syndrome (CRPS). As a result, diagnostic tools developed for adults (e.g., Budapest Criteria, Japanese Diagnostic Criteria, Veldman criteria) are frequently applied in the pediatric population. However, the clinical presentations and trajectories of children can differ from adults. Given that treatment outcomes are linked to early diagnosis and intervention, the lack of pediatric specific screening or diagnostic tools is an important knowledge gap. We aim to identify the frequency of individual criteria used in diagnosing CRPS in children and adolescents in existing literature, summarize assessment methods used to establish the diagnosis, and provide recommendations for research and clinical application.

Methods The following databases and platforms will be searched for articles published from 2003 (year the Budapest Criteria was developed) onward: CINAHL, CENTRAL, Embase, Ovid MEDLINE, PubMed, PsycINFO, and Web of Science. Our search strategy will use subject headings and text words related to the concepts of CRPS in pediatric populations, with study inclusion criteria from birth up to 18 years old, and a diagnosis of CRPS. Data will be extracted by our multidisciplinary team and findings will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews. **Ethics and dissemination** This study does not involve human participants or unpublished data, therefore approval from a human research ethics committee is not required. The findings of this scoping review will be disseminated through academic conferences and peer-reviewed publications.

Strengths and limitations of this study

- This scoping review will systematically identify the frequency of criteria used in diagnosing pediatric CRPS, thereby addressing an important gap in the literature.
- Through an analysis of applied diagnostic criteria, this scoping review will provide suggestions for pediatric specifications for CRPS and recommendations for clinical practice and implementation.
- Findings on the frequency of diagnostic criteria for CRPS in children and adolescents are expected to be heterogeneous. However, this will provide a foundation for developing a systematic approach to standardize diagnosis and facilitate further psychometric evaluation.

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Introduction

Complex regional pain syndrome (CRPS) is a chronic pain condition that presents with severe pain, affecting the distal extremities ¹. This is accompanied by altered sensory perception such as hyperalgesia and/or allodynia, vasomotor, trophic and autonomic dysfunction ^{2,3}. There may be an inciting event (e.g., trauma), however, no causes may be identified in pediatric populations ⁴. The clinical presentation of debilitating pain, skin discoloration, temperature changes, swelling, and hyperhidrosis of the affected region is highly distressing for children and adolescents, leading to significant pain-related disability ⁵. The incidence of pediatric CRPS is estimated to be 1.14/100,000 children per year ⁶. The underlying pathophysiology remains poorly understood, and it is hypothesized that dysfunction within the somatosensory system, combined with a complex interplay of biopsychosocial risk factors contributes to its manifestation ^{7–10}.

There are challenges in formulating the diagnosis of CRPS, as there are no confirmatory objective test(s) or biological markers. In adults, validated diagnostic criteria have been developed, such as the Budapest Criteria ¹¹, which was formally adopted by the International Association for the Study of Pain (IASP) in 2003 following a consensus conference in Budapest. Those criteria have since been identified as the gold standard for diagnosis of CRPS in adults ⁴. Unfortunately, research remains nascent on the development and validation of diagnostic criteria in pediatric populations. Given this limitation, adult diagnostic criteria have been applied clinically and in research studies for children ¹². However, based on age and developmental stage, the transferability is questionable as clinical characteristics, symptom trajectory and response to treatment in children differ from adults ^{6,13,14}. For example, involvement of the lower extremities is more common in children, and trophic changes are similarly uncommon ¹³. Furthermore, studies also suggest that symptoms in children are milder, and the longitudinal trajectory seems more favorable compared to adults ¹¹. Recognizing that the developmental, neurocognitive and behavioral differences can also impact clinical presentation and evaluation,

the direct application of adult diagnostic criteria for children may inadvertently result in delayed or inaccurate diagnoses and inappropriate care. As treatment outcomes (e.g., physical functioning, pain severity) have been linked to early diagnosis and intervention ¹³, the lack of pediatric-specific screening or diagnostic tools for CRPS is a significant research and knowledge gap.

Given the lack of pediatric specific diagnostic tool, the Budapest Criteria is commonly used to diagnose CRPS in pediatric populations ^{15,16}. However, in findings from a systematic review on pediatric CRPS, the majority of studies (> 50%) used authors' own criteria and/or assigned the diagnosis based upon clinician expertise, further highlighting this research gap in diagnostic consistency ¹⁵. More recently, research has advanced in the work by Mesaroli and colleagues, who developed a pediatric screening tool, the Pediatric PainSCAN. Preliminary validation efforts focused on establishing content validity for pediatric CRPS and neuropathic pain ¹⁷. This measure has yet to undergo additional psychometric testing, limiting its application to date.

Besides formulating pediatric specific criteria, methods of clinical assessment for identifying each criterion within the diagnostic tool should be considered ¹⁸. The process of obtaining a history and physical examination to evaluate for presence of clinical features can differ dramatically between children and adults, as would be expected given the age-related developmental, cognitive, behavioral and communication considerations. Moreover, children's neurological and physiological development undergo constant changes across the pediatric lifespan, lending to potential differences within the pediatric age groups ¹⁹. A pediatric focused tool should incorporate these multidimensional factors in order to address these differences.

Taken together, there is a need to identify the diagnostic criteria used for diagnosing CRPS in pediatric populations and to systematically characterize the criteria that have been used in previous studies, including authors' own criteria and clinician assessments. Therefore, the objectives of this scoping review are to identify the frequency of individual criteria used in diagnosing CRPS in children and summarize the assessment methods used to establish the

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diagnosis. Finally, based on our results, we will provide recommendations for use of the diagnostic criteria in pediatric clinical practice and research.

Methods and analysis

This proposed scoping review will be reported in accordance with the PRISMA-ScR guidelines, and is registered with the Open Science Framework (OSF: https://osf.io/j8mp3/).

Eligibility criteria

Participants

We are interested in studies on participants ages birth up to 18 years old, with a clinical diagnosis of CRPS. Studies should include any type of established diagnostic criteria (e.g., Budapest Criteria, Veldman Criteria) and those as defined by authors (e.g., symptoms, signs). If studies include samples that span a larger age range into early adulthood, e.g., 14 - 21 years, they can be included, when either, the mean age is below 18 years, with a maximum age of < 24 years, as previously recommended for pediatric pain research ²⁰, or outcomes are reported separately for patients ≤18 years ²¹.

Types of evidence sources

This scoping review will include published peer-reviewed full text articles written in English, presenting original data with retrospective or prospective study designs, including case reports, case series, case-control, cross-sectional, time-series, longitudinal cohort, and randomized-controlled trials studies. Commentaries may be included if the inclusion criteria are met and original data are presented. The following types of articles will be excluded: reviews (e.g., narrative, scoping, systematic), meta-analyses, clinical trial registrations, letters to the editor, opinion articles, essays, dissertations, conference abstracts, posters, books, book reviews, and book chapters.

Search Strategy

Before undertaking this review, the PROSPERO database was searched for ongoing or recently completed systematic reviews and/or meta-analyses on the same topic. A research librarian

(EN) with expertise in evidence synthesis will develop search strategies to reflect the concepts outlined in Table 1 below. A PubMed search strategy was developed with input from the project team, and then peer reviewed by a second librarian, not otherwise associated with the project. The intended PubMed search strategy is included below (Appendix 1). This search strategy will be adapted to the syntax of the other databases/platforms, using search words for the title and abstract fields and controlled vocabulary whenever possible.

The following databases/platforms will be searched: APA PsycINFO (EBSCOHost), CINAHL (EBSCOHost), Cochrane Central Register of Controlled Trials (Wiley), Embase.com, Ovid MEDLINE, PubMed (PubMed-Not-Medline and PubMed In-Process), and Web of Science (WOS, MEDLINE, SCIELO). Searches will be limited to human studies and published from 2003 onward, because the most established CPRS criteria, the Budapest Criteria, were introduced at this time. As relevant studies are identified, we will check for additional relevant cited and citing articles.

Data management and study selection

Search results will be exported into Covidence, a web-based software by Cochrane to assist with the production of reviews (https://www.covidence.org), to enable the identification and removal of duplicates. Study selection will be based on the previously described inclusion/exclusion criteria. For each record, two team members will independently perform the screening process on the title/abstract level as well as the full text assessment. Any disagreements during the screening process will be resolved by a third reviewer, and, if necessary, through discussions in the research team.

Data extraction plan

A customized, standardized extraction form will be used, and data will be organized in a customized extraction form specifically structured for this scoping review. We will extract information on authors, year of publication, countries of study conduct, study aims, study design, sample size, measures for diagnosis of CRPS, individual diagnostic criteria for CRPS,

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additional symptoms and signs related to CRPS but not part of diagnostic criteria defined in measures, assessment procedures (e.g. history vs. examination; type of procedure; specific instructions on the evaluation process and interpretations rules), measures assessing psychosocial functioning (e.g., of anxiety, depression, posttraumatic stress disorder, critical life events). Reviewers will be trained on using the data extraction form, and we will pilot the data extraction form on a sample of studies to ensure a common understanding amongst the reviewers Next, independent data extraction of 5 randomly selected publications will be conducted by at two reviewers, followed by discussion of disagreements amongst the entire team. After reaching agreement, subsequent data extraction for each study will be conducted by one team member. The reliability of extraction will be reviewed by a second team member throughout the extraction process, through regular checks to validate the extracted data.

Data synthesis

A search decision flow chart will present the number of studies identified, excluded, and included in accordance with the PRISMA-ScR guidance. Data will be summarized and analyzed descriptively, and study characteristics will be presented in tabulated format. We will determine the frequency of using measures for diagnosis of CRPS, individual diagnostic criteria for CRPS, additional symptoms and signs related to CRPS (but not part of diagnostic criteria), and the inclusion of measures that assessed psychosocial functioning. Based on this quantification, we will present the most prominent signs/symptoms across diagnostic tools/criteria.

Ethics and dissemination

This study does not involve human participants or unpublished secondary data. Approval from a human research ethics committee is not required. The results of this scoping reivew will be disseminated through peer-reviewed publications, academic conferences and professional societies.

Patient and Public Involvement

While patients and the public were not directly involved in the initial development of the scoping review protocol design, we plan to engage relevant patient representatives (e.g., children, caretakers) and advocacy groups (e.g., International Association for the Study of Pain, Complex Regional Pain Syndrome Special Interest Group) during the interpretation of results and dissemination phase. Future engagement strategies may include co-produced dissemination materials to ensure that the outcomes of this review are meaningful and applicable to the medical and patient communities.

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Table 1. Concepts and key terms for search blocks

MeSH	"pediatrics"[MeSH]	"complex regional pain syndromes"[MeSH]
	"infant"[MeSH]	
	"child"[MeSH]	
	"child, hospitalized"[MeSH]	
	"adolescent"[MeSH]	
	"adolescent hospitalized"[MeSH]	
	"minors"[MeSH]	
	"young adult"[MeSH]	
synonyms	pediatric*	algodystrophic syndrome
	adolescent	algodystrophy
	boy	algoneurodystrophy
	child	causalgia
	girl	chronic regional pain syndrome
	juvenile	complex regional pain syndrome
	kid	CRPS
	minor	Morbus Sudeck
	pubescent	post-traumatic dystrophy
	preadolescence	reflex sympathetic dystrophy
	teen	sympathetic dystrophy
	young adult	sympathetic reflex dystrophy
	youth	Sudeck's atrophy/disease/syndrome
		Sudeck Leriche syndrome
		type 1 regional pain syndrome

*Plural forms and alternate spellings will be included, for example, pediatric and pediatrics.

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Authors' contributions: Study idea conception: SWT, RL, LR, NS, LF, JW, HK Study design: SWT, RL, LR, NS, LF, EN, JW, HK Writing of the protocol: SWT, RL, LR, NS, LF, EN, JW, HK Approval of the final version: SWT, RL, LR, NS, LF, EN, JW, HK Study conduct, acquisition of data, analysis and interpretation of data: not applicable; this manuscript describes a study protocol. SWT is the guarantor. Funding statement: SWT is supported by National Institute of Health NIDDK (K23DK118111). HK is supported by a Swiss National Science Foundation Ambizione Grant (PZ00P1 208850). LF is supported by the UK Medical Research Council (MR/X010716/1). RL is supported by a Career Development Fellowship award from Versus Arthritis (Grant 23199). Competing interests statement: None declared

Appendix 1

Example PubMed search strategy

("pediatrics"[MeSH Terms] OR "child"[MeSH Terms] OR "child. hospitalized"[MeSH Terms] OR "adolescent"[MeSH Terms] OR "adolescent, hospitalized"[MeSH Terms] OR "minors"[MeSH Terms] OR "young adult"[MeSH Terms] OR "paediatric*"[Title/Abstract] OR "pediatric*"[Title/Abstract] OR "adolescen*"[Title/Abstract] OR "boy"[Title/Abstract] OR "boys*"[Title/Abstract] OR "child*"[Title/Abstract] OR "children*"[Title/Abstract] OR "girl*"[Title/Abstract] OR "juvenile*"[Title/Abstract] OR "kid"[Title/Abstract] OR "kids*"[Title/Abstract] OR "minor*"[Title/Abstract] OR "minors*"[Title/Abstract] OR "pre adolescen*"[Title/Abstract] OR "preadolescen*"[Title/Abstract] OR "preteen*"[Title/Abstract] OR "pubescen*"[Title/Abstract] OR "teen*"[Title/Abstract] OR "teenage*"[Title/Abstract] OR "young adult*"[Title/Abstract] OR "young individual*"[Title/Abstract] OR "young man"[Title/Abstract] OR "young men"[Title/Abstract] OR "young person*"[Title/Abstract] OR "young people*"[Title/Abstract] OR "young woman*"[Title/Abstract] OR "young women*"[Title/Abstract] OR "youngster*"[Title/Abstract] OR "youth*"[Title/Abstract]) AND ("complex regional pain syndromes"[MeSH Terms] OR "algodystroph*"[Title/Abstract] OR "algoneurodystroph*"[Title/Abstract] OR "causalgia*"[Title/Abstract] OR "chronic regional pain syndrome*"[Title/Abstract] OR "complex regional pain syndrome*"[Title/Abstract] OR "crps*"[Title/Abstract] OR "morbus sudeck"[Title/Abstract] OR "post traumatic dystroph*"[Title/Abstract] OR "posttraumatic dystroph*"[Title/Abstract] OR "reflex sympathetic dystroph*"[Title/Abstract] OR "sudeck* atroph*"[Title/Abstract] OR "sudeck* disease"[Title/Abstract] OR "sudeck* dystroph*"[Title/Abstract] OR "sudeck leriche syndrome*"[Title/Abstract] OR "sudeck* syndrome*"[Title/Abstract] OR "sympathetic dystroph*"[Title/Abstract] OR "sympathetic reflex dystroph*"[Title/Abstract]) AND 2003/01/01:2024/12/31[Date - Publication] AND "english"[Language]