

## Report Supplementary Material File 1

### Characteristics of Excluded Studies

Study	Title	Reason for Exclusion
Abadesso 2020	Pain in Children and Adolescents with Sickle Cell Disease: Multidimensional Assessment	Wrong publication type
Ahola 2016	Being a peer mentor to youth with painful chronic conditions: Perceived benefits and challenges	Wrong publication type
Ahola 2017	Been There, Done That: The Experience of Acting as a Young Adult Mentor to Adolescents Living with Chronic Illness	Wrong population
Alavi 2012	Indignity, exclusion, pain and hunger: the impact of musculoskeletal impairments in the lives of children in Malawi	Wrong population
Albasri 2022	Using art workshops to facilitate research priority settings: Identifying research questions with primary school children with juvenile idiopathic arthritis	Wrong publication type
Alhowimel 2022	Psychosocial consequences of diagnosing nonspecific low-back pain radiologically: a qualitative study	Wrong population
Allgood 2015	A phenomenological study of pain in individuals with cystic fibrosis	Wrong publication type
Allyn 2020	"Tomorrow, I'll Be Fine": Impacts and coping mechanisms in adolescents and young adults with primary dysmenorrhoea	Wrong population
Alongi 2018	Differences in the perception of disease impact between us and Italian children with juvenile idiopathic arthritis: A network analysis of virtual focus groups	Wrong publication type
Amory 2019	I Dont Feel Like I Have Any Control of My Life at All . . . Everything Overwhelms Me. Everything: Analyzing Caregiver Uncertainty and Control Through Stance Marking	Wrong population
April 20	Acceptability and usability testing of a preliminary version of the JIA option map, an electronic decision aid for pain management options in juvenile idiopathic arthritis	Wrong publication type
Arbabisarjou 2014	The perception of biological experience in patients with major Thalassemia: a qualitative research	Duplicate
Arbabisarjou 2015	The perception of biological experience in patients with major Thalassemia: a	Wrong population

	qualitative research	
Arbitre 2019	Patients' and caregivers' experiences with pain management in children and teenagers with sickle cell disease requiring admission for vaso-occlusive crisis	Wrong publication type
Arbitre 2019a	Patients' and caregivers' experiences with pain management in children with sickle cell disease	Wrong publication type
Arbuckle 2010	Child and parent reports of symptoms of irritable bowel syndrome with constipation (IBS-C): Results of qualitative interviews	Wrong publication type
Arruda 2017	Yoga for youth with inflammatory bowel disease: A pilot feasibility study	Wrong publication type
Arruda 2018	Yoga as adjunct therapy for adolescents with inflammatory bowel disease: A pilot clinical trial	Wrong population
Atkin 1998	Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals	Unavailable by deadline
Aziato 2015	Dysmenorrhea Management and Coping among Students in Ghana: A Qualitative Exploration	Wrong population
Baert 2020a	Mothers' appraisals of injustice in the context of their child's chronic pain: An interpretative phenomenological analysis	Duplicate
Bailey 2018	Content validation of the sickle cell pain diary-self report	Wrong publication type
Bailey 2018a	Content validation of sickle cell pain diaries for caregivers: Results from interviews with caregivers	Wrong publication type
Bakshi 2015	Development, Content Validity, and User Review of a Web-based Multidimensional Pain Diary for Adolescent and Young Adults with Sickle Cell Disease	Wrong publication type
Barlow 1998a	The experience of parenting in the context of juvenile arthritis	Duplicate
Barned 2022	"The Rest of my Childhood was Lost": Canadian Children and Adolescents' Experiences Navigating Inflammatory Bowel Disease	Wrong population
Beales 1983	The child's perception of the disease and the experience of pain in juvenile chronic arthritis	Unavailable by deadline
Becker 2019	The Experience of Pain and Pain Tool Preferences of Hospitalized Youth	Wrong population
Bennett 2000	Evaluating treatment outcome in an interdisciplinary pediatric pain service	Wrong publication type
Bennett 2000a	Parent Perceptions of the Impact of Chronic Pain in Children and Adolescents	Wrong publication type
Beresford 2003	Chronically ill adolescents' experiences of communicating with doctors: a	Wrong population

	qualitative study	
Beyer 1999	Practice guidelines for the assessment of children with sickle cell pain	Wrong publication type
Bieniak 2022	Hypermobile Ehlers-Danlos syndrome: Caregiver child concordance across challenges, readiness to change, and coping	Wrong publication type
Birks 2008	Adolescents learned self-management of arthritis by acquiring knowledge and skills and experiencing understanding from social support	Wrong publication type
Borghì 2014a	Living with pain: the experience of children and adolescents in palliative care	Wrong population
Borghì 2016	"Living with pain-the life from childrens and adolescents in palliative care"	Wrong publication type
Borini 2021	Suffered life, hard life: adverse experiences in childhood of people with chronic musculoskeletal pain	Wrong population
Bousso 2014	Expressions of a teenager under palliative care on facebook	Wrong publication type
Bousso 2015	Expressions of teenagers under palliative care on facebook: A fresh approach for healthcare professionals	Wrong publication type
Branson 2011	Managing chronic pain in a young adolescent girl with Ehlers-Danlos syndrome	Wrong publication type
Britton 1999	A Pilot Study exploring Families' Experience of Caring for Children with Chronic Arthritis: Views from the Inside	Wrong population
Brown 2021	Pediatric patient reported outcomes in patients receiving voxelotor for sickle cell disease	Wrong publication type
Buchanan 2018	An initial examination of parent satisfaction following intensive rehabilitation for pediatric chronic pain	Wrong publication type
Buchbinder 2011	Children's pain and the ethics of care	Unavailable by deadline
Buesa-EstÀlez 2022	Uso de la balneoterapia y el ejercicio terapÀutico en la mejora fÀsica y psicosocial en adolescentes con lupus y artritis juvenil: un estudio de mÀtodo mixto	Wrong publication type
Burke 2016	The 10-item sickle cell disease severity measure (SCDSM-10): A novel measure of daily SCD symptom severity developed to assess benefit of GBT440, an experimental HbS polymerization inhibitor	Wrong publication type
Byczkowski 2016	Family-Centered Pediatric Emergency Care: A Framework for Measuring What Parents Want and Value	Wrong population
Caes 2019	Pain and quality of life in youth with inflammatory bowel disease: the role of parent and youth perspectives on family functioning	Wrong publication type

Cai 2017	Developing and Evaluating JIApp: Acceptability and Usability of a Smartphone App System to Improve Self-Management in Young People with Juvenile Idiopathic Arthritis	Wrong population
Calhoun 2022	Transition for Adolescents and Young Adults with Sickle Cell Disease in a US Midwest Urban Center: A Multilevel Perspective on Barriers, Facilitators, and Future Directions	Wrong population
Cappon 2020	Feasibility of the back-and-forth school booklet, a shared self-management instrument for young children with juvenile idiopathic arthritis (JIA) at school	Wrong publication type
Cappon 2021	Applicability and effectiveness of the back-and-forth school booklet, a shared self-management instrument for young children with juvenile idiopathic arthritis (JIA) at school	Wrong publication type
Carlson 2012	Focus group assessment of reported food intolerances (RFIS) and quality of life (QOL) in children with abdominal pain-related functional gastrointestinal disorders (APFGIDs)	Wrong publication type
Carlson 2014	Child and Parent Perceived Food-Induced Gastrointestinal Symptoms and Quality of Life in Children with Functional Gastrointestinal Disorders	Wrong publication type
Carter 1998	Children and their experience of pain.	Unavailable by deadline
Carter 2016	'Left to get on with it': The experiences of parents of children with profound cognitive impairment managing their child's pain	Wrong publication type
Carter 2017a	Being Me (with IBD): growing up and getting on with my life	Wrong publication type
Carter 2020	"I Don't Like to Make a Big Thing out of It": A Qualitative Interview-Based Study Exploring Factors Affecting Whether Young People Tell or Do Not Tell Their Friends about Their IBD	Wrong population
Castro 2020	The day-to-day experiences of caring for children with Osteogenesis Imperfecta: A qualitative descriptive study	Wrong population
Chadi 2018	Comparison of an in-person vs. ehealth mind-fullness meditation-based intervention for adolescents with chronic medical conditions: A mixed methods study	Wrong publication type
Chakravorty 2017	Using a new patient feedback survey to explore experiences of living with Sickle Cell Disease in the UK	Wrong publication type
Chaplin 2018	The impact of juvenile idiopathic arthritis on adolescents and young adults: A	Wrong publication type

	qualitative study	
Chaplin 2018a	Exploring pain and the impact of Jia on adolescents and young adults: A mixed methods study	Wrong publication type
Chaplin 2019	Exploring refractory disease & persistent symptoms in RA/polyjia despite bDMARDs: Patient & professional experiences	Wrong publication type
Childs 1998	Expressed emotion, pain describing and family response behaviours in individuals with chronic pain	Wrong population
Christian 1997	The child's eye: memories of growing up with cystic fibrosis	Wrong population
Claar 2007	Parent and Child Perceptions of Chronic Pain Treatments	Wrong publication type
Clery 2021	Qualitative study of the acceptability and feasibility of acceptance and commitment therapy for adolescents with chronic fatigue syndrome	Wrong population
Coleman 2016	How sickle cell disease patients experience, understand and explain their pain: An Interpretative Phenomenological Analysis study	Wrong population
Colver 2018	How well do services for young people with long term conditions deliver features proposed to improve transition?	Wrong population
Cooke 2021	myPainPal: Co-creation of a mHealth app for the management of chronic pain in young people	Wrong population
Cotton 2009	Religious/Spiritual coping in adolescents with sickle cell disease: a pilot study	Wrong population
Crego 2021	Patient Perspectives of Sickle Cell Management in the Emergency Department	Wrong population
Crosby 2022	Perceptions of a self-management intervention for adolescents with sickle cell disease	Wrong population
Cunningham 2018a	A patient-engaged approach to refining a psychological therapy for individuals with childhood-onset lupus	<del>Duplicate</del> Wrong publication type
Cunningham 2019a	A patient-engaged approach to refining a psychological therapy for individuals with childhood-onset lupus	Wrong publication type
Dahal 2018	A study to extrapolate the lived-in experience of parents of children with chronic illness in SRM general hospital, Kattankulathur	Wrong population
Davis 2016	Making connections: Exploring social and relational influences for young people experiencing and coping with chronic pain	Wrong publication type
de Graaf 2017	Duration of intravenous antibiotic therapy for children with acute osteomyelitis or septic arthritis: a feasibility study	Wrong population

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Dekker 2020	Pain-related fear in adolescents with chronic musculoskeletal pain: process evaluation of an interdisciplinary graded exposure program	Wrong publication type
de Lucca 2016	Fatherhood: experiences of fathers of boys diagnosed with Duchenne Muscular Dystrophy	Wrong publication type
de Souza 2011	Sickle-cell disease: short communication on how children express through games what it means for them to have the disease	Wrong publication type
Department of Public Health Sciences, 1998	Living with Sickle Pain Report Á Sickle Cell Society	Wrong publication type
Dickson 2002	Quality of life in children with headache	Unavailable by deadline
Diehl 1991	Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings	Wrong population
DiGiacomo 2018	Interacting With Providers: An Intersectional Exploration of the Experiences of Carers of Aboriginal Children with a Disability	Wrong population
Donovan 2022	The acceptability of photovoice as a method for incorporating resilience-enhancing factors into pediatric pain research	Wrong population
Dunford 2014	Parental behaviour in paediatric chronic pain: A qualitative observational study	Wrong publication type
Easterlin 2020	Child and Family Perspectives on Adjustment to and Coping with Pediatric Inflammatory Bowel Disease	Wrong population
Eaves 2014	Modes of hoping: understanding hope and expectation in the context of a clinical trial of complementary and alternative medicine for chronic pain	Wrong population
Eaves 2015	Works of Illness and the Challenges of Social Risk and the Specter of Pain in the Lived Experience of TMD	Wrong population
Eaves 2016	Ways of Hoping: Navigating the Paradox of Hope and Despair in Chronic Pain	Wrong population
Ebrahimpour 2019	Children's description of pain through drawings and dialogs: A concept analysis	Wrong publication type
Elander 2019	Development and validation of the Satisfaction with Treatment for Pain Questionnaire (STPQ) among patients with sickle cell disease	Wrong publication type
Elliott 1997	The experiences of mothers caring for a child with severe atopic eczema	Wrong population
El 2018	Juvenile inflammatory arthritis: The development and validation of an illustrated questionnaire to measure children's motivation	Wrong publication type
Ely 1992	The Experience of Pain for School-Age Children: Blood, Band-Aids, and	Wrong population

	Feelings	
Ely 2016	The pain experience of hospitalized youth: Assessment and management preferences	Wrong publication type
Engel 1991	Behavioral assessment of chronic headaches in children	Wrong publication type
Esteve 2012	Children's pain perspectives	Wrong publication type
Evans 2010a	Sex-specific associations between parent and child pain and functioning in a pediatric chronic pain sample: A mixed methods approach	Wrong publication type
Eyckmans 2011	What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients	Wrong population
Fairhurst 2013	Functional deterioration in severe adolescent hemidystonia	Wrong publication type
Farrell 2012	The role of cognitive interviews in the development of pain behavior and pain quality item banks for pediatrics: A Patient Reported Outcomes Measurement Information System (PROMIS) study	Wrong publication type
Farrugia 2018	Long-term art therapy intervention for a teenage girl with chronic pain and enthesitisrelated JIA	Wrong publication type
feSouza 2011	To have Sickle Cell Anemia: a preliminary note about its significance for children as expressed through their play	Wrong publication type
Fidanci 2013	Living with childhood vasculitis; a qualitative study	Wrong publication type
Fleitas 2000	When Jack fell down ... Jill came tumbling after. Siblings in the web of illness and disability	Wrong population
Flores 2017	The Charla de Lupus (lupus chat) program: Assessing the needs of teens and young adults with lupus and their caregivers to develop a family model nutrition and fitness intervention	Wrong publication type
Forgeron 2008a	Self-identified needs of youth with chronic pain	Unavailable by deadline
Forgeron 2011	Social interactions of adolescents with chronic pain: Are they different?	Wrong publication type
Forgeron 2019	Support for My Video is Support for Me: A YouTube Scoping Review of Videos Including Adolescents with Chronic Pain	Duplicate
Forgeron 2019a	Support for my video is support for me	Duplicate
Forrest 2020	Establishing the content validity of PROMIS Pediatric pain interference, fatigue, sleep disturbance, and sleep-related impairment measures in children with chronic kidney disease and Crohn's disease	Wrong publication type

Forrester 2015	The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica	Wrong population
Garrett 2015	Sickle cell disease and the family: A phenomenological study	Wrong population
Ghio 2011	Investigating children's beliefs about juvenile arthritis: A study using cognitive interviewing	Wrong publication type
Ghio 2015	Validating a pain perception questionnaire for young people with juvenile arthritis	Wrong publication type
Gordon 2021	Examining experiences of acute and chronic pain among individuals with sickle cell disease (SCD) in Jamaica and cameroon	Wrong publication type
Graff 2012	Exploring Family Communication About Sickle Cell Disease in Adolescence	Wrong population
Grant 2019	Conceptual Model to Illustrate the Symptom Experience and Humanistic Burden Associated with Atopic Dermatitis in Adults and Adolescents	Wrong population
Gravelle 1997	Caring for a child with a progressive illness during the complex chronic phase: parents experience of facing adversity	Wrong population
Gray 2013	Context is everything: Supporting young people taking medication for arthritis	Wrong publication type
Gray 2014	Context is everything: Supporting young people taking medication for arthritis	Wrong publication type
Gray 2014a	Arthriting-insights about the links between identity, arthritis and medication in the blogs of young people living with juvenile arthritis	Wrong publication type
Griffiths 2017	Collaborating with burn patients and their families to develop the CARE Burn Scales: A portfolio of burn-specific quality of life PROMs for use in paediatric and adult burn care	Wrong publication type
Gross 2017	Pain Management for Children in Emergency Departments - Primum Non Nocere	Wrong publication type
Group 2018	Adherence in Youth with Multiple Sclerosis: A Qualitative Assessment of Habit Formation, Barriers, and Facilitators	Wrong population
Gulhati 1998	Parental health attitudes, illnesses and supports and the referral of children to medical specialists	Wrong publication type
Gupta 2018	How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers? Findings from focus group discussions in New York City	Wrong population
Guzman 2013	What matters the most for parents, patients and clinicians in predicting the	Wrong publication type



	course of juvenile idiopathic arthritis (JIA)?	
Guzman 2013a	What is the relative priority of the ACR pediatric core set measures for youth with juvenile idiopathic arthritis and their parents?	Wrong publication type
Guzman 2014	What matters most for patients, parents, and clinicians in the course of juvenile idiopathic arthritis? A qualitative study	Wrong publication type
Hall 2019	Improving the Patient Experience with Migraine Camp, a One-Day Group Intervention for Adolescents with Chronic Headache and Their Parents	Wrong publication type
Hallberg 2009	Fitting into the prevailing teenage culture: A grounded theory on female adolescents with chronic arthritis	Wrong publication type
Hanson 2018	Experiences of employment among young people with juvenile idiopathic arthritis: a qualitative study	Wrong population
Harris 2017	A qualitative investigation of eating difficulties in adolescents with chronic fatigue syndrome/myalgic encephalomyelitis	Wrong population
Harry 2018	Adolescents' perspectives on living with childhood-onset systemic lupus erythematosus	Wrong publication type
Harry 2018a	Living with childhood-onset systemic lupus erythematosus: A focus group with caregivers	Wrong publication type
Harry 2019	Adolescents' perspectives on living with childhood-onset systemic lupus erythematosus	Wrong publication type
Harry 2019a	Self-management and adherence in childhood-onset systemic lupus erythematosus: what are we missing?	Wrong population
Hart 2014	Being as normal as possible: How young people value the risks and benefits of treatment	Wrong publication type
Hatchette 2005	Pain self-management in adolescents: A psychosocial approach to understanding the acquisition of knowledge, attitudes and behaviors	Wrong population
Hatchette 2006	Maternal influences in adolescents' pain self-management: A qualitative investigation	Wrong population
Hatchette 2008	The role of peer communication in the socialization of adolescents' pain experiences: a qualitative investigation	Wrong population
Haukeland 2015	Emotional Experiences Among Siblings of Children with Rare Disorders	Wrong population
Hawkins 2019	Experience of chronic transfusion therapy in sickle cell disease: A qualitative	Wrong population

	study	
Hawkins 2020	Patient and family experience with chronic transfusion therapy for sickle cell disease: A qualitative study	Duplicate
Hayes 2008	Fathers' perspectives on the emotional impact of managing the care of their children with cystic fibrosis	Wrong population
Helms 2008	Physiology and treatment of pain	Unavailable by deadline
Henderson 2014	Why go online when you have pain? A qualitative analysis of teenagers' use of the Internet for pain management advice	Wrong population
Hexem 2013	Putting on a Happy Face: Emotional Expression in Parents of Children with Serious Illness	Wrong publication type
Higginson 2019	Moving on: Transition experiences of young adults with chronic pain	Wrong population
Hildenbrand 2015	Coping and coping assistance among children with sickle cell disease and their parents	Wrong publication type
Hill 2022	Living with osteogenesis imperfecta: A qualitative study exploring experiences and psychosocial impact from the perspective of patients, parents and professionals	Wrong population
Hind 2017	Aquatic therapy for children with Duchenne muscular dystrophy: a pilot feasibility randomised controlled trial and mixed methods process evaluation	Wrong population
Horne 2017	A qualitative investigation of recovery after femoral fracture in Rett syndrome	Wrong population
Horonjeff 2016	Reconsidering the juvenile idiopathic arthritis core SET: How patients and caregivers define disease activity	Wrong publication type
Hulgaard 2019	Illness perceptions of youths with functional disorders and their parents: An interpretative phenomenological analysis study	Wrong population
Hummelinck 2006	Parents' information needs about the treatment of their chronically ill child: a qualitative study	Wrong population
Humphrey 2018	A qualitative study of the experience of adults and adolescents with ulcerative colitis	Wrong publication type
Hunfeld 2001	Chronic pain and its impact on quality of life in adolescents and their families	Wrong publication type
Hunfeld 2002	Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: A three-year follow-up	Wrong publication type
Hurley-Wallace	Online paediatric chronic pain management: assessing the needs of UK	DuplicateWrong publication type

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2020	adolescents and parents, using a cross-sectional survey	
Hurley-Wallace 2021	Online paediatric chronic pain management: assessing the needs of UK adolescents and parents, using a cross-sectional survey	Wrong publication type
Hurley-Wallace 2022	Exploring Internet needs for the management of adolescent chronic pain: developing digital interventions in context	Wrong publication type
Hurtubise 2020	Using collaborative logic analysis evaluation to test the program theory of an intensive interdisciplinary pain treatment for youth with pain-related disability	Wrong publication type
Hutchinson 2007	A phenomenological exploration of the patient learning J experiences of 16–19-year-old women accessing a young people's rheumatology service in the UK	Wrong population
Ingeman 2022	Health anxiety by proxy - through the eyes of the parents	Wrong population
Inusa 2013	What do preliminary analyses highlight as the key fears and worries of children and young people with sickle cell disease and what can we do to support them?	Wrong publication type
Inusa 2015	Overnight respiratory support for prevention of morbidity in sickle cell disease (POMS 2A)-parent and child preferences	Wrong publication type
Jacob 2005	Are there phases to the vaso-occlusive painful episode in sickle cell disease?	Wrong publication type
Jacobs 2020	Which passengers are on your bus? A taxonomy of the barriers adolescents with chronic pain face in achieving functional recovery	Wrong population
Jacobson 2011	Accounts of chronic pain and emotional distress in children and youth with juvenile idiopathic arthritis or chronic pain: Qualitative analysis of interviews to assess content validity of the patient reported outcome measurement information system	Wrong publication type
Jacoby 2020	Illness Narratives Through the Eyes of Parents of Children with End-Stage Renal Disease	Wrong population
Jansathong 2002	Northern Thai school-aged children pain experience: pain descriptions and pain management strategies	Unavailable by deadline
Jerrett 1994	Parents' experience of coming to know the care of a chronically ill child	Wrong population
Jimenez 2021	Usefulness of complementary test in the study of patients with chronic abdominal pain	Wrong population
Johansen 2022	PAINSTORIES - Exploring the Temporal Developments in the Challenges, Barriers, and Self-Management Needs of Adolescents with Longstanding Knee Pain: A Qualitative, Retrospective Interview Study with Young Adults	Wrong population

	Experiencing Knee Pain Since Adolescence	
Johnson 2000	Mothers' Perceptions of Parenting Children with Disabilities	Wrong population
Johnson 2015	Development of a patient-reported outcome measure in pancreatic exocrine insufficiency (PEI)	Wrong publication type
Jones 2019	My future: using story completion methods to examine how adolescents with complex regional pain syndrome think about their future	Wrong publication type
Jongudomkarn 2006	The meanings of pain: A qualitative study of the perspectives of children living with pain in north-eastern Thailand	Wrong population
Jongudomkarn 2008	Families in northeast Thailand - Living with a child in pain	Wrong population
Joslin 2022	Communication preferences of young people experiencing persistent musculoskeletal pain	Wrong publication type
Josset-Raffet 2016	Bodily and psychic trajectory of pain in children with sickle cell disease	Wrong publication type
Kenyon 2012	Setting the agenda for quality improvement in pediatric sickle cell disease	Wrong population
Khanom 2019	Exploring the experience of pain flares in adolescent inflammatory and non-inflammatory musculoskeletal disorders: A phenomenological study	Wrong publication type
Khanom 2020a	Characterizing pain flares in adolescent inflammatory and non-inflammatory musculoskeletal disorders: A qualitative study using an interpretative phenomenological approach	Duplicate
Khazendar 2021	User-centered development of a digital exposure treatment for youth with chronic pain	Wrong publication type
Khemani 2016	Experiences and decision making for bone marrow transplant in sickle cell disease: Patients and caregivers' perspective	Wrong publication type
Khemani 2018	Experiences and Decision Making in Hematopoietic Stem Cell Transplant in Sickle Cell Disease: Patients and Caregivers Perspectives	Wrong population
KimHyun 2011	Lived Experience of Women with Severe Dysmenorrhea	Wrong population
Kirk 2012	Perceptions of effective self-care support for children and young people with long-term conditions	Wrong population
Kirschbaum 1996	Life support decisions for children: What do parents value?	Wrong population
Knafl 1992	Parents' views of health care providers: an exploration of the components of a positive working relationship	Wrong population
Kohut 2018	The internet as a source of support for youth with chronic conditions: A	Wrong population

	qualitative study	
Kohut 2020	Feasibility and Acceptability of a Mindfulness-Based Group Intervention for Adolescents with Inflammatory Bowel Disease	Wrong population
Kohut 2021	Resilience Factors in Paediatric Inflammatory Bowel Disease: Health Care Provider, Parent and Youth Perspectives	Wrong population
Kortesuoma 2004	'I had this horrible pain': the sources and causes of pain experiences in 4- to 11-year-old hospitalized children	Wrong population
Kortesuoma 2006	'The most disgusting ever': children's pain descriptions and views of the purpose of pain	Wrong population
Kortesuoma 2008	"You just have to make the pain go away"--children's experiences of pain management	Wrong population
Kortesuoma 2008a	Hospitalized children drawing their pain: the contents and cognitive and emotional characteristics of pain drawings	Wrong publication type
Korus 2011	Exploring the information needs of adolescents and their parents throughout the kidney transplant continuum	Wrong population
Korving 2021	Pain recognition in children and adults with rare genetic syndromes and intellectual disability	Wrong population
Kosakowski 2022	Patient Perspectives on Improving Patient-Provider Relationships and Provider Communication During Opioid Tapering	Wrong population
Kristjansdottir 2000	Familial aggregation and pain theory relating to recurrent pain experiences in children	Wrong publication type
Kvarnstram 2012	How Service Users Perceive the Concept of Participation, Specifically in Interprofessional Practice	Wrong population
Kwarteng-Siaw 2017	Transition readiness assessment of adolescents with sickle cell disease and their caretakers at the sickle cell clinic in Kumasi, Ghana	Wrong publication type
Laflamme 2020	Enablers of psychosocial recovery in pediatric burns: perspectives from the children, parents and burn recovery support staff	Wrong population
Lagerlov 2016	How adolescents experience and cope with pain in daily life: a qualitative study on ways to cope and the use of over-the-counter analgesics	Wrong population
Lai 2012	Quality-of-life measures in children with neurological conditions: Pediatric Neuro-QOL	Wrong publication type

Lai 2017	Using a Qualitative Approach to Conceptualize Concerns of Patients with Neurofibromatosis Type 1 Associated Plexiform Neurofibromas (pNF) Across the Lifespan	Wrong publication type
Lalla 2010	Using patient focus groups to inform economic modeling: Experience from a hemophilia patient focus group	Wrong publication type
Laloo 2013	"There's a pain app for that": Promoting pain self-management among adolescents and young adults	Wrong population
Laloo 2013a	Clinical feasibility of the iconic pain assessment tool from the perspective of adolescents with chronic pain and their multi-disciplinary team of healthcare providers	Wrong publication type
Laloo 2014	Pain-QuILT: Assessing Clinical Feasibility of a Web-based Tool for the Visual Self-Report of Pain in an Interdisciplinary Pediatric Chronic Pain Clinic	Wrong population
Lanis 2021	Storytelling of young adults with chronic rheumatologic illnesses: A pilot study	Wrong publication type
Latimer 2014	Expression of pain among Mi'kmaq children in one Atlantic Canadian community: a qualitative study	Wrong population
Latimer 2018	Creating a safe space for First Nations youth to share their pain	Wrong population
Latimer 2020	Co-creating better healthcare experiences for First Nations children and youth: The FIRST approach emerges from Two-Eyed seeing	Wrong population
Lauderdale 2003	The lived experience of African American adolescents with sickle cell disease	Unavailable by deadline
Laursen 2019	Morality in clinical space: treatment of youngsters with functional somatic symptoms in a Western clinical context	Wrong population
Law 2016	Problem-solving therapy for parents of children receiving intensive pain rehabilitation	Wrong publication type
Law 2021	Longitudinal study of early adaptation to the coronavirus disease pandemic among youth with chronic pain and their parents: Effects of direct exposures and economic stress	Wrong population
Le 2017	Development and Usability Evaluation of an Art and Narrative-Based Knowledge Translation Tool for Parents with a Child with Pediatric Chronic Pain: Multi-Method Study	Wrong publication type
Lee 2022	'Because that's their job, isn't it? Exploring children and young people's experiences of and perspectives about pain communication in paediatric	Wrong publication type

	rheumatology in the UK	
Lerner 2018	Implications of a paediatrician-psychologist tandem for sickle cell disease care and impact on cognitive functioning	Wrong publication type
Lesane-Brown 2012	Parent-child communication about sickle cell disease	Wrong publication type
Lewandowski 2005	Exploring family resiliency: adolescents with multiple neurosurgeries and chronic pain	Wrong publication type
Lewis 2007	The Princess and the pain: an exploration of the therapeutic efficacy of personalised story telling for children in chronic pain	Unavailable by deadline
Lewis 2010	Development of pediatric irritable bowel syndrome with constipation measures: Results of qualitative interviews with children and their parents	Wrong publication type
Lewis 2018	Does the role of food in the self-management of pain in teens with juvenile arthritis vary based on gender or ethnicity?	Wrong publication type
Lewis 2018a	The role of food in the self-management of pain in teens with Juvenile arthritis: Gender and ethnic differences	Wrong publication type
Lim 2011	Why parental education is needed in a paediatric chronic pain clinic	Wrong publication type
Lindsay 2013	Disclosure, accommodations and self-care at work among adolescents with disabilities	Wrong population
Liossi 2012	How parents make sense of their young children's expressions of everyday pain: a qualitative analysis	Wrong population
Lipstein 2013	"I'm the one taking it": adolescent participation in chronic disease treatment decisions	Wrong population
Livermore 2016	The lived experience of juvenile idiopathic arthritis in young people receiving etanercept	Wrong population
Ilfors 2003	Pain coping and well-being in children with chronic arthritis	Unavailable by deadline
Lloyd 2014	From symptom onset to diagnosis: A critical exploration into the experiences of young people with juvenile systemic lupus erythematosus (JSLE)	Wrong publication type
Lundberg 2021	How children with juvenile idiopathic arthritis view participation and communication in healthcare encounters: a qualitative study	Wrong population
MacGregor 2018	The value of education workshops for patients and families in the management of pediatric headache	Wrong publication type
Maciver 2011a	Parental experiences of pediatric chronic pain management services	Duplicate

Maciver 2013	Parental experiences of pediatric chronic pain management services	Duplicate
Maciver 2014	Parental experiences of pediatric chronic pain management services	Duplicate
Mackner 2014	Focus Groups for Developing a Peer Mentoring Program to Improve Self-Management in Pediatric Inflammatory Bowel Disease	Wrong population
Maikler 2001	Childrens' and Adolescents' Use of Diaries for Sickle Cell Pain	Wrong publication type
Malcolm 2014	A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study	Wrong population
Mather 2008	An investigation of childhood trauma, dissociation and body-focused attention in medically unexplained symptoms	Wrong publication type
McDonagh 2016	Sometimes I feel like a pharmacist: identity and medication use among adolescents with juvenile arthritis	Wrong population
McGurgan 2021	Parental experiences of psychological interventions for recurrent abdominal pain in childhood	Wrong population
McKinnon 2020a	The lived experience of chronic pain in children with dyskinetic cerebral palsy from the perspective of carers	Wrong publication type
McLeod-Fletcher 1996	Appraisal and coping with vaso-occlusive crisis in adolescents with sickle cell disease	Unavailable by deadline
McLeod-Fletcher 1997	Appraisal and coping with vaso-occlusive crisis in adolescents with sickle cell disease	Duplicate
Meldrum 2009	'Just be in pain and just move on': Functioning limitations and strategies in the lives of children with chronic pain	Wrong population
Melville 2014	Development of a comprehensive support website for parents of children with juvenile idiopathic arthritis	Wrong publication type
Merlijn 2005	A cognitive-behavioural program for adolescents with chronic pain--a pilot study	Wrong publication type
Merolli 2014	Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain	Wrong population
Miettunen 2017	Giving children a voice through art: To understand and educate about the impact of juvenile idiopathic arthritis by creating art and telling digital stories	Wrong publication type
Mihelicova 2016	Caring for people with severe myalgic encephalomyelitis: An interpretative phenomenological analysis of parents' experiences	Wrong population
Miller 2016	Injustice perceptions predict future functioning in children with chronic pain	Wrong publication type



Miller 2021	Engagement during a Mixed In-Person and Remotely Delivered Psychological Intervention for Youth with Functional Abdominal Pain Disorders and Anxiety	Wrong publication type
Missen 2012	The financial and psychological impacts on mothers of children with chronic fatigue syndrome (CFS/ME)	Wrong population
Mitchell 2002	Information that informs rather than alienates families with disabled children: developing a model of good practice	Wrong population
Mittinty 2022	Building evidence to reduce inequities in management of pain for Indigenous Australian people	Wrong population
Modi 2009	Barriers to Treatment Adherence for Pediatric Patients with Sickle Cell Disease and Their Families	Wrong publication type
Modica 2016	Impact of systemic juvenile idiopathic arthritis/still's disease on adolescents as evidenced through social media posting	Wrong publication type
Modica 2017	Impact of systemic juvenile idiopathic arthritis/Still's disease on adolescents as evidenced through social media posting	Wrong publication type
Modica 2018	Impact of systemic juvenile idiopathic arthritis/Still's disease on adolescents as evidenced through social media posts	Wrong population
Moghadam 2021	Experiences of Iranian female patients with systemic lupus erythematosus: A qualitative study	Wrong population
Molloy 2017	NIV in Duchenne muscular dystrophy: A qualitative study	Wrong publication type
Monsen 1999	Mothers' experiences of living worried when parenting children with spina bifida	Wrong population
Monterosso 2007	Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service	Wrong population
Mora 2017	The gender vulnerability contexts of chronic pain	Wrong population
Morgan 2018	New consensus on an updated core domain set for clinical trials in juvenile idiopathic arthritis	Wrong population
Mosor 2019	"When you read this, you really feel old!" perspectives of young people with inflammatory arthritis on patient reported outcome measures from a European qualitative study	Wrong publication type
Mufti 2014	Pakistani Childrens' Experiences of Growing Up with Beta-Thalassemia Major	Wrong population
Mufti 2015	Pakistani children's experiences of growing up with beta-thalassemia major	Wrong population

Mulchan 2016	Applicability of the SMART Model of Transition Readiness for Sickle-Cell Disease	Wrong population
Mulvogue 2009	Relief-oriented use of marijuana by teens	Wrong population
Murray 2022	Healthcare Transition Among Young Adults with Childhood-Onset Chronic Pain: A Mixed Methods Study and Proposed Framework	Wrong population
Nabors 2017	Perceptions of Hospitalization by Children with Chronic Illnesses and Siblings	Wrong population
Namisango 2020	Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study	Wrong population
Navarro 2018	Parenting young people with complex regional pain syndrome: an analysis of the process of parental online communication	Wrong population
Ndengeyingoma 2021	Youngsters' perceptions of the experience of pain and utilisation of over-the-counter pain medication as needed in community: A qualitative study	Wrong population
Neville 2021	Pediatric Chronic Pain in the Midst of the COVID-19 Pandemic: Lived Experiences of Youth and Parents	Wrong population
Newton 2018	A qualitative study into the experience of adolescents and adults with ulcerative colitis	Wrong publication type
Newton 2021	A qualitative study to explore symptoms and impacts of pediatric and adolescent Crohn's disease from patient and caregiver perspective	Wrong population
Nicholas 2011	The lived experiences of children and adolescents with end-stage renal disease	Wrong population
Nichols 2015	Patterns of interaction between factors that enhance or inhibit recovery from chronic low back pain	Wrong population
Nkhoma 2021a	Modelling an appropriate pain self-management intervention for adolescents with HIV/AIDS in Malawi	Wrong publication type
Nkoy 2019	Information needs for designing a home monitoring system for children with medical complexity	Wrong population
Noel 2016	Characterizing the Pain Narratives of Parents of Youth with Chronic Pain	Wrong publication type
Nsangou 2020	Sickle cell anemia and projection into the future: A comprehensive approach to the experiences of a sick child's sister in Cameroon	Wrong publication type
Nyante 2019	The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study	Wrong population

Oddy 2000	The development of a social psychological chronic pain scale through utilisation of a qualitative-quantitative facilitation paradigm	Wrong publication type
Ojo 2018	Measurement of sickle cell disease symptoms from the patient perspective: Considerations for clinical trials	Wrong publication type
Ojo 2018a	What matters to individuals with Sickle cell disease? Patient input on the relevant and important symptoms and impacts of the condition.	Wrong publication type
Oreper 2022	Defining Success in Transitions from Pediatric to Adult Chronic Pain Care: A Descriptive Qualitative Study of Perspectives of Young Adults Living with Chronic Pain	Wrong population
Ortiz 2014	The health of caregivers of children with chronic disability and the rehabilitation impact on them	Wrong publication type
Ostojic 2019	Biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy	Wrong publication type
Ostojic 2020	BrightHearts: A pilot study of biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy	Wrong publication type
Ostojic 2020a	Biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy	Wrong publication type
Packham 2014	Content Validity of the Patient-Report Hamilton Inventory for Complex Regional Pain Syndrome	Wrong publication type
Packham 2020	Persons with Complex Regional Pain Syndrome Renegotiate Social Roles and Intimacy: A Qualitative Study	Wrong population
Palermo 2014	Adaptation of Problem-Solving Skills Training (PSST) for Parent Caregivers of Youth with Chronic Pain	Wrong publication type
Palsgrove 2014	Burden of autosomal dominant polycystic kidney disease (ADPKD): Effects on the daily lives of patients and their caregivers	Wrong publication type
Panepinto 2011	The development of the PedsQLTM sickle cell disease module items: Qualitative methods	Wrong publication type
Pantaleao 2019	Caregiver factors related to emergency department utilization for youth with sickle cell disease	Wrong population
Park 2000	"The Worst Hassle Is You Can't Play Rugby": Haemophilia and Masculinity in New Zealand	Wrong population
Peck 2018	A Perspective on Adolescent Chronic Pain Dismissal	Wrong publication type

Pelaez-Ballestas 2013	'Not-belonging': illness narratives of Mexican patients with ankylosing spondylitis	Wrong population
Pendleton 2002	Religious/spiritual coping in childhood cystic fibrosis: a qualitative study	Wrong population
Peters 2017	What is the role of the clinical nurse specialist in a multi-disciplinary, chronic pain management service for young people, in a tertiary hospital in London?	Wrong publication type
Polkki 1997	"It feels like a hedgehog quill sticking in my foot...". School-aged children's experience of pain in the hospital	Unavailable by deadline
Polkki 1997a	It feels like a hedgehog sticks in my foot... school-aged children's experiences of pain in hospital	Duplicate
Polkki 1999	Pain in children: qualitative research of Finnish school-aged children's experiences of pain in hospital	Wrong population
Pousette 2019	Experiences of Being a Parent to a Child with Amelogenesis Imperfecta	Wrong population
Preston 2016	Living with an invisible illness	Wrong publication type
Pritchard 2012	Systematic ethnography of school-age children with bleeding disorders and other chronic illnesses: exploring children's perceptions of partnership roles in family-centred care of their chronic illness	Wrong population
Qualter 2020	Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition	Wrong publication type
Quintanar-Solares 2013	Using questionnaire design to explore reporting differences for spasticity related pain in children and adolescents with cerebral palsy	Wrong publication type
Resha 2015	Understanding Pain in Children with Sickle Cell Disease	Wrong publication type
Rabbitts 2017	Long-Term Pain and Recovery After Major Pediatric Surgery: A Qualitative Study with Teens, Parents, and Perioperative Care Providers	Wrong population
Ramlee 2017	Sleep and physical activity: a mixed method study in people with chronic pain	Wrong population
Randall 2019	Ulcerative colitis experiences among children: Findings from a qualitative study with children and parents	Wrong publication type
Rich 2000	Video intervention/prevention assessment: a patient-centered methodology for understanding the adolescent illness experience.	Wrong population
Risko 2018a	Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Program	Duplicate

Roberts 2021	Reflections beyond words: using auto-driven photo-elicitation to explore the pain management programme journey	Wrong population
Rodrigues 2017	Evaluation of family management of an adolescent with Sickle cell disease	Wrong population
Roper 2018	Children's and parents' perspectives on outcomes for JIA trials comparing different corticosteroid delivery routes: A qualitative study	Wrong publication type
Ross 1984	Childhood pain: the school-aged child's viewpoint	Wrong population
Rossato 2011	The experience of child in pain with juvenile idiopathic arthritis	Wrong publication type
Rossato 2014	Assessment of pain in children and adolescents in palliative care	Wrong publication type
Roth 2018	Ethnography of integrative pain management at a large urban pediatric hospital	Wrong population
Roth 2019	Employing Evidence in Evaluating Complementary Therapies: Findings from an Ethnography of Integrative Pain Management at a Large Urban Pediatric Hospital	Wrong population
Roth 2020	Implementation strategies used in a pediatric integrative pain management pilot consult service: Findings from an ethnography	Wrong publication type
Rouse 2011	Informing choice or teaching submission to medical authority: a case study of adolescent transitioning for sickle cell patients	Wrong population
Rousseau 2007	Children as young as 4 years of age with type 1 diabetes showed understanding and competence in managing their condition	Wrong population
Ruddy 2019	Exploring the experiences of parent caregivers of children with chronic medical complexity during pediatric intensive care unit hospitalization: an interpretive descriptive study	Wrong population
Rullander 2013	Young People's Experiences with Scoliosis Surgery...A survey of pain, nausea, and global satisfaction	Wrong population
Ruskin 2014	The development of a mindfulness-based stress reduction group for adolescents with chronic pain	Wrong publication type
Sallfors 1999	Experience of pain at a group of children with juvenile chronic arthritis	Unavailable by deadline
Salvo 2022	The journey of Living with Pain: A feasibility study of the development and running of a collective narrative group	Wrong publication type
Sangha 2021	Psychosocial impact of epidermolysis bullosa on patients: A qualitative study	Wrong population
Santos 2013	The impact of chronic health conditions: Learning from osteogenesis imperfecta (OI) patients and their families	Wrong population

Santos 2017	Parental beliefs on the impact of obesity in pediatric pain	Wrong publication type
Savedra 1981	Description of the pain experience: a study of school-age children	Wrong publication type
Schonbachler 2020	Der Alltag von Jugendlichen mit einer Sichelzellerkrankung - Eine qualitative, explorative und partizipative Photovoice-Studie	Wrong population
Schultz 2010	Family living through sickness and child's hospitalization: qualitative study	Wrong population
Schulz 2014	Spinal manipulation and exercise for low back pain in adolescents: study protocol for a randomized controlled trial	Wrong publication type
Scorgie 1996	A qualitative study of managing life when a child has a disability.	Wrong population
Seangrung 2021	Perspectives of pain specialists, patients, and family members on long-term opioid use for chronic non-cancer pain: a qualitative study	Wrong population
Shaw 2004	User perspectives of transitional care for adolescents with juvenile idiopathic arthritis	Wrong population
Sil 2021	The comfort ability program for adolescents with sickle cell pain: Evaluating feasibility and acceptability of an inpatient group-based clinical implementation	Wrong publication type
Simon 1992	Living with chronic pediatric liver disease: the parents' experience	Wrong population
Simons 2020	Developing a Framework to Support the Delivery of Effective Pain Management for Children: An Exploratory Qualitative Study	Wrong population
Skarstein 2020	How do mothers of adolescents with chronic pain experience their own quality of life?	Wrong population
Slater 2016	Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study	Wrong population
Smeland 2019	Children's views on postsurgical pain in recovery units in Norway: A qualitative study	Wrong population
Smith 2018	Parent Perspectives on Pain Management in Preschool-Age Children with Sickle Cell Disease	Wrong publication type
Smith 2022	A qualitative exploration of the impact of persistent pain	Wrong population
Snelgrove 2015	Youth with Chronic Illness Forming Identities through Leisure	Wrong population
Snyder 2001	An exploration of treatment interference in children hospitalized in a pediatric intensive care unit	Wrong population
Solodiuk 2020	The Use of Music by Adolescents and Young Adults with Sickle Cell Disease	Unavailable by deadline

Solomon 2016	'What Brings Him Here Today?': Medical Problem Presentation Involving Children with Autism Spectrum Disorders and Typically Developing Children	Wrong population
Solyom 2017	Defining the clinical impact of symptoms in a diverse population of patients with a rare disease: A qualitative research study in acid ceramidase deficiency (Farber disease)	Wrong publication type
Sparapani 2015	What Is It Like to Be a Child with Type 1 Diabetes Mellitus?	Wrong population
Sparud-Lundin 2018	Reaching Independence Through Forced Learning: Learning Processes and Illness Management in Parents of Children Affected by Hemophilia	Wrong population
Spiers 2016	Transforming community health services for children and young people who are ill: a quasi-experimental evaluation	Wrong population
Stebbins 2018	Barriers to treatment for patients with sickle cell disease: Results from in-depth interviews with patients and caregivers	Wrong publication type
Stebbins 2018a	Impact of sickle cell disease on work, school, relationships, and social life: Results from in-depth interviews with patients	Wrong publication type
Stefanatou 1997	Depiction of pain in the self-drawings of children with sickle cell disease	Wrong publication type
Stegenga 2004	Quality of life among children with sickle cell disease receiving chronic transfusion therapy	Wrong population
Stenekes 2009	Frequency and self-management of pain, dyspnea, and cough in cystic fibrosis	Wrong publication type
Stenner 2016	Exercise prescription for non-specific chronic low back pain (NSCLBP): a qualitative study of patients' experiences of involvement in decision making	Wrong population
Stewart 2011	Brief report: An online support intervention: Perceptions of adolescents with physical disabilities	Wrong population
Stinson 2006	e-Ouch: usability testing of an electronic chronic pain diary for adolescents with arthritis	Wrong population
Stinson 2015	Development and usability testing of an IPAD-based psycho-educational game for children with juvenile idiopathic arthritis and their parents	Wrong publication type
Stinson 2016	Development and usability testing of an iPad and desktop psycho-educational game for children with Juvenile Idiopathic Arthritis and their parents	Wrong publication type
Stinson 2016a	iCanCope with Pain: User-centered design of an integrated smartphone and web-based pain self-management program for youth and young adults with chronic pain	Wrong publication type

Stratton 2011	Experiencing stress	Wrong population
Suder 2017	The Lived Experience of Adolescents with Chronic Pain: A Phenomenological Study	Wrong publication type
Svedberg 2010	Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support	Wrong publication type
Swallow 2011	Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare?	Wrong population
Swallow 2013	Multidisciplinary teams, and parents, negotiating common ground in shared care of children with long-term conditions: a mixed methods study	Wrong population
Swift 2014	A new perspective on family involvement in chronic pain management programmes	Wrong population
Szentagotai 2005	Reprezentarea durerii la copii = Children's representation of pain	Unavailable by deadline
Tanabe 2013	Care of Children with Sickle Cell Disease in the Emergency Department: Parent and Provider Perspectives Inform Quality Improvement Efforts	Wrong population
Tapping 2015	Development and feasibility testing of a new iPad application, this feeling, to aid communication of pain in children with juvenile idiopathic arthritis	Wrong publication type
Tapping 2015a	"This feeling!": Can a new IPAD app help children with juvenile idiopathic arthritis communicate their pain experiences? feasibility, usability and acceptability	Wrong publication type
Taub 2000	Physical Activity as a Normalizing Experience for School-Age Children with Physical Disabilities: Implications for Legitimation of Social Identity and Enhancement of Social Ties	Wrong population
Tekano 2014	Children and parent satisfaction in the pediatric rheumatology clinic: Patient orientated quality service measures	Wrong publication type
Tetzl 2017	A qualitative research study documenting the clinical impact of symptoms in a diverse population of patients and caregivers with acid ceramidase deficiency (farber disease)	Wrong publication type
Timko 1992	Functioning among mothers and fathers of children with juvenile rheumatic disease: a longitudinal study	Wrong publication type
Toupin-April 2018	First steps in developing a novel decision support intervention for pain	Wrong publication type



	management options in juvenile idiopathic arthritis	
Toupin-April 2018a	Exploring decision making needs about pain management among adolescents with juvenile idiopathic arthritis and their families: Preliminary results from interviews	Wrong publication type
Toupin-April 2020	Development and Acceptability of a Patient Decision Aid for Pain Management in Juvenile Idiopathic Arthritis: The JIA Option Map	Wrong population
Trennery 2019	Qualitative patient research to support the development of a conceptual model to illustrate the experience of atopic dermatitis in adolescents	Wrong publication type
Treves 1999	The management of insomnia on a residential pain management programme: a single case series and qualitative analysis	Wrong population
Trope 2018	Referential skills participatory in JIA for children, adolescents and parents	Wrong publication type
Tuchman 2008	Transition to adult care: experiences and expectations of adolescents with a chronic illness	Wrong population
Unruh 1983	Children's drawings of their pain	Wrong publication type
Vaienzuela 2010	Empowering youth with sickle cell disease; A photovoice pilot	Wrong publication type
Vaira-Joyce 2022	What are the experiences of identity development in young adult women who had chronic pain in adolescence?	Wrong population
vanStaa 2011	"What we want": chronically ill adolescents' preferences and priorities for improving health care	Wrong population
Varni 2011	PedsQLTM gastrointestinal symptoms module item development: Qualitative methods	<del>Duplicate</del> Wrong population
Varni 2012	PedsQL gastrointestinal symptoms module item development: qualitative methods	Wrong publication type
Vendetti 2016	A new measure assessing recovery from a sickle cell crisis	Wrong publication type
Venner 2014	Health education for sickle cell disease: Strategies to support families and health care workers in Tanzania	Wrong publication type
Vera 2015	The lived experience of pain in adolescents diagnosed with cystic fibrosis	Wrong publication type
Vervoort 2008	Expressive dimensions of pain catastrophizing: A comparative analysis of school children and children with clinical pain	Wrong publication type
Vine 2020	Improving transitions in care for children with complex and medically fragile needs: a mixed methods study	Wrong population

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Visram 2013	Development of conceptual and process models of growing pains: A mixed-method research design	Wrong population
Visram 2017	Impact and acceptability of lay health trainer-led lifestyle interventions delivered in primary care: a mixed method study	Wrong population
vonScheven 2021	Research Questions that Matter to Us: priorities of young people with chronic illnesses and their caregivers	Wrong population
Vuorimaa 2013	Cultural adaptation of the "teens taking charge: Managing arthritis online" program to Finland	Wrong publication type
Wainwright 2022	Beliefs About Worry and Pain Amongst Adolescents with and Without Chronic Pain	Wrong population
Waite-Jones 2008	Concealed concern: fathers' experiences of having a child with juvenile idiopathic arthritis	Wrong population
Wakefield 2020	"it'll Go Away. There's Nothing Wrong with you:" The Experience of Pain-Related Stigma among Adolescents with Pain Amplification Syndrome	Wrong publication type
Ware 2014	Coping and adjustment among adolescents with sickle cell disease	Wrong publication type
Warnink-Kavelaars 2019	Marfan syndrome in childhood: parents' perspectives of the impact on daily functioning of children, parents and family; a qualitative study	Wrong population
Warnink-Kavelaars 2019a	Marfan syndrome in adolescence: adolescents' perspectives on (physical) functioning, disability, contextual factors and support needs	Wrong population
Webb 2011	What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)	Wrong population
Wells 2013	'It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies	Wrong population
Wihak 2020	Development and feasibility testing of the Comfort Ability Program for sickle cell pain: A patient-informed, video-based pain management intervention for adolescents with sickle cell disease	Wrong publication type
Williams 2001	Alert assistants in managing chronic illness: the case of mothers and teenage sons	Wrong population
Williams 2011	The experiences of young people with Epidermolysis Bullosa Simplex: a qualitative study	Wrong population

Witwicki 2015	Piloting a new Patient Reported Experience Measure for Sickle Cell Disease: A report of the findings	Wrong publication type
Wong 2019	Feasibility of the learning and exercise to avert pain (LEAP) programme: An evaluation of a group therapy intervention for young people with chronic musculoskeletal pain	Wrong publication type
Wren 2021	Mindfulness-Based Virtual Reality Intervention for Children and Young Adults with Inflammatory Bowel Disease: A Pilot Feasibility and Acceptability Study	Wrong population
Wren 2022	Dismissal, distrust, and dismay: A phenomenological exploration of young women's diagnostic experiences with endometriosis and subsequent support	Wrong population
Wright 2015	'It's hard but you've just gotta get on with it'--The experiences of growing-up with a liver transplant	Wrong population
Young 2020	Let Their Voices Be Seen	Wrong population
Zabalia 2013	Pediatric pain assessment: A pragmatic analysis of dialogues in the interactions of healthcare providers, children and their parents	Wrong publication type
Zeevenhooven 2020	A Core Outcome Set for Clinical Trials in Pediatric Functional Abdominal Pain Disorders	Wrong publication type
Zengin 2017	Evaluation of biopsychosocial aspects of patients with juvenile Behcet's disease: A qualitative study	Wrong publication type