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Lived and care experiences of young people with chronic musculoskeletal pain and mental health conditions: a systematic review with qualitative evidence synthesis

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Abstract

Chronic musculoskeletal pain (CMP) and coexisting mental health conditions impact young people; however, little is known about their lived and care experiences. In a prospectively registered systematic review with qualitative evidence synthesis (PROSPERO: CRD42022369914), we explored the following: (1) lived physical, psychological, and social experiences; and (2) care experiences/preferences of young people living with CMP and mental health conditions. Inclusion criteria: studies using qualitative methods; participants aged 16 to 24 years with CMP and coexisting mental health condition(s); phenomenon explored included lived and/or care experiences. Seven databases were searched (inception to 19-May-2024), study quality was assessed, data were extracted and analysed thematically, and GRADE-CERQual was used to assess confidence in findings. Twenty-two studies (23 reports) were included (>239 participants, 82% women). Lived experiences yielded 4 themes (9 findings): 2-way relationship between CMP and mental health (2 findings, low to moderate confidence); psychosocial implications of CMP (3 findings, very low-moderate confidence); uncertainty about future (2 findings, low-moderate confidence); coping with CMP and mental health conditions (2 findings, low-moderate confidence). Care experiences/preferences yielded 3 themes (8 findings): navigating healthcare systems (2 findings, moderate confidence); receiving appropriate care (3 findings, very low-moderate confidence); point-of-care experiences and care preferences (3 findings, very low-moderate confidence). Chronic musculoskeletal pain and mental health conditions are interconnected, significantly impacting young people's lives, identities, and socialisation, yet services for CMP and mental health are often inadequate and poorly integrated. The mechanisms and interplay of CMP and mental health require deeper exploration, including how young people may be better supported with personalised, holistic, developmentally and/or life-stage-appropriate integrated care.

Keywords: Young people, Chronic musculoskeletal pain, Mental health, Qualitative evidence synthesis

1. Introduction

The lives of young people transitioning from adolescence to young adulthood (defined here as 16-24 years) can be profoundly impacted when experiencing coexisting chronic musculoskeletal pain (CMP) and mental health conditions. Chronic musculoskeletal pain is considered as pain manifesting in musculoskeletal structures and persisting continuously or intermittently, for 3 months or longer,[51] while mental health conditions are aligned with the description from the World Health Organization (WHO), "a broader term covering mental disorders, psychosocial disabilities and (other) mental states associated with significant distress, impairment in functioning, or risk of self-harm."[82]

Chronic musculoskeletal pain and mental health conditions commonly coexist in young people; however, most prevalence data

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are represented as aggregated children/adolescents or adult data. Prevalence data for this specific age range indicate a global pooled point prevalence for nonspecific CMP in 15- to 34-year-olds of 18.3% (95% CI: 14.0-23.7) and 18.3% (95% CI: 8.4-35.6) for localized CMP.[47] Globally, the prevalence of mental disorders for people aged 15 to 19 years is 14.0% (95% UI, 12.36-15.78), and 13.6% (95% UI, 11.90-15.53) for people aged 20 to 24 years.[33] To our knowledge, global prevalence data for coexisting CMP and mental health disorders are not available for this age range. However, Australian national data indicate that at ages 16 to 24 years, almost half (49%) of people with a musculoskeletal condition also experience a comorbid mental disorder.[3] While prevalence and disability estimates help characterize the scale of burden, understanding the lived experience of interactions between CMP and mental health and their impact remains critical to informing care for young people.[2,84]

Currently, interpreting evidence for beneficial care is challenged by findings (quantitative and qualitative) that are typically aggregated and binarized into paediatric and adult populations. Furthermore, while the relationship between CMP and mental health is recognised as bidirectional,[28,59] our understanding of this interaction in young people is also limited: a critical gap to informing transdiagnostic holistic care. From qualitative research of 15- to 18-year-olds from the United Kingdom, lived experiences of comorbid pain and mental health conditions were highly disruptive to young people's ability to regulate their physical, psychological, and social wellbeing; however, key transitional care experiences and preferences were not explored.[15] Other qualitative literature including 16- to 24-year-olds has identified a consistent influence of pain on mental health and vice versa.[32,50,65,79] However, a rich exploration of the intersection of these coexisting conditions is lacking.

Existing studies have not exclusively sampled young people and were not specific to young people living with CMP that span across ICD-11 classifications. This is important as young people might experience multiple CMP conditions,[69] underscoring the need for a transdiagnostic care approach to both CMP and mental health issues. In addition, evidence gathered from different developmental age groups may not be applicable to others. Moreover, primary qualitative studies are context- and population-specific, rendering broader generalisation and mapping of impacts and relationships difficult in the absence of a meta-synthesis. A nuanced and in-depth understanding of the interaction between lived experiences and care preferences/needs of young people experiencing coexisting CMP and mental health conditions would help characterise how care can be better targeted and integrated to support their needs.

Therefore the research questions for this systematic review and qualitative evidence synthesis (QES) were as follows:

1. What are the lived physical, psychological, and social experiences of young people (16-24 years) experiencing CMP and mental health conditions?
2. What are the care experiences, preferences, and/or priorities of young people (16-24 years) experiencing CMP and mental health conditions?

2. Materials and methods

2.1. Study design

A prospectively registered systematic review of studies using qualitative methods was conducted (PROSPERO registration: CRD42022369914, 10-November-2022). The review is reported according to the Enhancing Transparency in the Reporting and Synthesis of Qualitative Research (ENTREQ) checklist[75] and the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) checklist[57] (Supplementary files 1 and 2, http://links.lww.com/PAIN/C135, respectively).

2.2. Inclusion and exclusion criteria

Criteria for studies eligible for inclusion included the following:

1. primary qualitative studies that used designs such as ethnography, phenomenology, grounded theory, case studies, and qualitative process evaluations; or studies that use qualitative methods for both data collection (eg, focus group discussions, individual interviews, observation, diaries, document analysis, open-ended survey questions) and analysis (eg, thematic analysis, framework analysis, grounded theory), which may include nested qualitative studies or mixed-methods studies with a qualitative component;
2. studies where participants were young people with a lived experience of CMP (either actively experiencing it or had recovered) and coexisting mental health condition(s) (**Table 1**)[84];
3. studies where the phenomenon explored included the lived and/or care experiences of young people with coexisting CMP and mental health conditions (**Table 1**).

We excluded comments, editorials, letters, news pieces, clinical trials, and review articles and did not include grey literature sources. We excluded studies where the primary/index health condition for sampling was not CMP (eg, pregnancy, people with developmental impairments), where lived and/or care experiences of CMP and mental health conditions were not explored, and where only the voices of the parents/guardians/clinicians were reported. No restrictions were placed on publication language or health care or community settings.

See Supplementary files 3 and 4, http://links.lww.com/PAIN/C135 for criteria summaries, presented in PerSPEcTiF[8] and SPIDER format,[12] respectively.

2.3. Search strategy and selection of studies

Seven electronic databases were initially searched (Ovid-Medline, Ovid-Embase, Ovid-PsycINFO, Ovid-AMED, EBSCO-CINAHL, SCOPUS, and Web of Science) without language restriction from inception until, 21-February-2023, with the search subsequently updated to 19-May-2024. Search terms were created by a specialist research librarian (L.R.) aligned to SPIDER criteria[12] (Supplementary file 4, http://links.lww.com/PAIN/C135), informed by seeding papers, and iterated in collaboration with the multidisciplinary research team reflecting expertise in physiotherapy, psychology, and pain medicine (A.M.B., H.S., N.R.K., R.S., S.L.).

The search strategy was checked against the Peer Review of Electronic Search Strategies (PRESS) Checklist[46] (Supplementary file 5, http://links.lww.com/PAIN/C135). The search strategy for the Ovid-Medline database is presented in Supplementary file 6, http://links.lww.com/PAIN/C135, as an example. Aggregated and de-duplicated citations were managed in Covidence (Veritas Health Innovation Ltd, Melbourne, Australia). From a pool of 7 reviewers (A.M.B., B.T., H.S., J.C., J.S., N.R.K., R.W.), pairs of reviewers independently screened titles and abstracts in Covidence to determine each citation's eligibility for inclusion. Conflicts were resolved by A.M.B. and H.S. Full texts of potentially eligible articles were independently reviewed by pairs of reviewers from a pool of 4 (A.M.B., B.T., H.S., R.W.) to confirm eligibility. Disagreements were resolved by A.M.B. and H.S. The reference lists of the included full-text studies were screened for additional citations by J.C. and N.R.K., using the same process as outlined above to determine eligibility for inclusion.

Table 1

Inclusion criteria, including sample and phenomena criteria.

Criteria	Operational definition
Sample criteria	
Young people	Defined as meeting at least one of the following criteria: mean age of a cohort falling between 16 and 24 y, or ≥75% of the cohort aged between 16 and 24 y, or data were able to be disaggregated by age, allowing for the extraction of data relevant to our age band of interest.
Chronic musculoskeletal pain (CMP)	Defined as pain manifesting in musculoskeletal structures that persisted either continuously or intermittently for at least 3 mo and was either primary or secondary based on International Classification of Disease (ICD)-11 classification, including neuropathic pain experienced in association with pain manifesting in musculoskeletal structures.[51] To be eligible for inclusion, at least 75% of the sample needed to be classified as experiencing CMP, or data were reported in a disaggregated manner, allowing a subset of data to be extracted relevant to this criterion. This threshold was pragmatically selected to ensure the dominant experience of the included sample reflected CMP and was aligned with similar thresholds used by WHO.[81]
Mental health condition	Defined in line with the WHO definition.[82] This definition was selected to capture participants with either or both diagnosed mental health conditions, or mental states associated with distress and impairments to functioning. Where studies did not explicitly state the impacts of CMP on mental health, evidence of mental health conditions was evaluated against the participants' quotes and second-order data. For example, where participants referred to emotional disruptions such as depression or anxiety, or cognitive disruptions such as rumination or worry, this was considered sufficient evidence of a mental health condition. To be eligible for inclusion, at least 75% of the sample needed to experience a mental health condition(s), or data were reported in a disaggregated manner, allowing a subset of data to be extracted relevant to this criterion. Where sample characteristic data were not reported or evidenced in supplementary files, to determine eligibility, authors were contacted for clarification.
Phenomena criteria	
Lived experiences	Defined as physical (eg, mobility, functional), psychological (eg, mood, emotions, thoughts, worry), or social (eg, interactions with friends, family, peers, and participation in school or work) experiences.
Care experiences	Defined as experiences relating to seeking or receiving any aspect of health or social care for CMP and mental health conditions by a young person. This phenomenon also included the young person's expectations, values and preferences, and priorities for their care.

2.4. Data extraction

Using a custom and prepiloted data extraction sheet, data for each included study were extracted independently by pairs of reviewers from a pool of 3 (J.C., N.R.K., S.R.). A composite data set was then created, where discordances were resolved through consensus with arbitration by A.M.B. or H.S. if required. Within this pool, no reviewer extracted data from a report (or arbitrated) on which they were a coauthor. Characterising data included citation information; aims; design; setting; methods including philosophical perspective/research paradigm, inclusion and

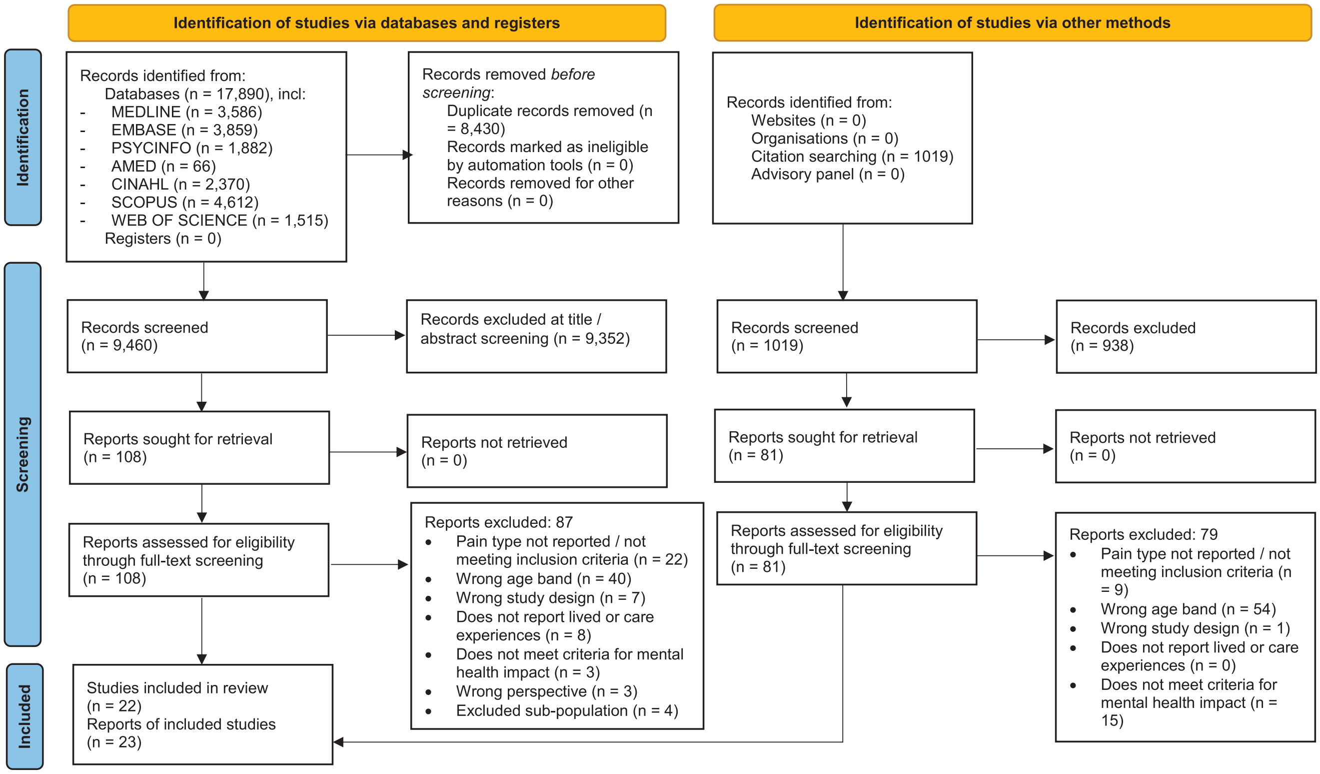

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart of included studies.

Table 2

Characteristics of the included reports (n = 23), including characteristics of subsets of cohorts, where applicable.

Report citation; country; geographic region*	Study design; methodology†	Recruitment setting; sampling method (data collection year)	Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡		CMP diagnosis	n (%)	Mental health condition§	n (%)
Bitencourt et al., 2021[5]; United States; North America	Cross-sectional qualitative study; not reported	Large public safety-net hospital clinic; purposive sampling (2020)	*Overall sample (n = 13)*					
			Female	13 (100)	Systemic lupus erythematosus	13 (100)	Not reported	
			Age, mean (range)	21 (18-24)				
			Pain duration	Since childhood, defined as childhood-onset SLE				
Corser et al., 2023[15]; United Kingdom; Europe	Cross-sectional qualitative study; phenomenology	Schools, pain clinics, social media; convenience sampling (2019)	*Overall sample (n = 7)*					
			Female	7 (100)				1 (14)
			Age	16.6 (1.8)	Hypermobility	1 (14)	Anxiety	7 (100)
			Pain duration, range	1-8 y	Fibromyalgia and hypermobility	1 (14)	Self-harm	2 (28)
					Fibromyalgia	1 (14)	Depression	5 (71)
					Hypermobility and scoliosis	1 (14)	Posttraumatic stress disorder	1 (14)
			Included subset from overall sample (n=5; 71%)					
			Female	5 (100)	Complex regional pain syndrome	3 (60)	Anorexia	1 (20)
			Age	17.6 (0.5)	Hypermobility and complex regional pain syndrome	1 (20)	Anxiety	5 (100)
			Pain duration, range	1-8 y	Fibromyalgia	1 (20)	Self-harm	1 (20)
							Depression	4 (80)
							Posttraumatic stress disorder	1 (20)

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Table 2 (*continued*)

Report citation; country; geographic region*	**Study design; methodology†**	**Recruitment setting; sampling method (data collection year)**	**Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡**		**CMP diagnosis**	**n (%)**	**Mental health condition§**	**n (%)**
Fawole et al., 2021[18]; United States and Canada; North America	Cross-sectional cohort study; Survey with nested free-text responses	Patient organisations; convenience sampling (2017-2018)	*Overall sample (n= 123)*‖					
			Female	115 (93)	Juvenile idiopathic arthritis	50 (41)	Any mental health	92 (75)
			Age bands, n (%)		Juvenile dermatomyositis	43 (35)	Depression	65 (53)
			12-17 y	46 (37)	Systemic lupus erythematosus	30 (24)	Anxiety	81 (66)
			18-24 y	77 (63)			Adjustment disorder	46 (37)
			Pain duration, median (IQR)	8 (5-12)			Suicidal thoughts	28 (23)
							Self-injury	15 (12)
							Posttraumatic stress disorder	10 (8)
							Bipolar disorder/psychosis	12 (10)
							Eating disorder	24 (20)
							Attention deficit disorder	25 (20)
							Oppositional defiant disorder	2 (2)
							Substance abuse/addiction	5 (4)
			Included subset from overall sample (n=not reported)¶					
			Female	Not reported				
			Age band, n (%)					
			17-24 y	Not reported	Not reported		Not reported	
			Pain duration	Not reported				
Goldenberg et al., 2013[22]; United States; North America	Longitudinal qualitative case study; not reported	Recruitment setting unclear; purposive sampling (not reported)	*Overall sample (n = 1)*					
			Female	0 (0)	Fibromyalgia	1 (100)	Not reported	
			Age	17				
			Pain duration	1.5				
Hale et al., 2014[25]; United States; North America	Cross-sectional qualitative study; interpretive phenomenological	Rheumatology clinic at large teaching hospital; purposive sampling (not reported)	*Overall sample (n = 15)*					
			Female	14 (93)	Systemic lupus erythematosus	15 (100)	Not reported	
			Age, range	22-57				
			Pain duration, range	3-20				
			Included subset from overall sample (n= 1; 7%)					
			Female	1 (100)	Systemic lupus erythematosus	1 (100)	Not reported	
			Age	22				
			Pain duration	12				

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Table 2 (*continued*)

Report citation; country; geographic region*	**Study design; methodology†**	**Recruitment setting; sampling method (data collection year)**	**Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡**		**CMP diagnosis**	**n (%)**	**Mental health condition§**	**n (%)**
Hanson et al., 2018[26]; United Kingdom; Europe	Multiphase cross-sectional qualitative study; qualitative description	Large UK-based teaching hospital with JIA service; purposive followed by theoretical sampling (2012-2014)	*Overall sample (n = 29)*					
			Female	19 (65.5)	Juvenile idiopathic arthritis	29 (100)	Not reported	
			Age	22 (3.7)				
			Pain duration	13.2 (5.6)				
			Included subset from overall sample (n = 23; 79%)					
			Female	16 (70)	Juvenile idiopathic arthritis	23 (100)	Not reported	
			Age	20 (2.4)				
			Pain duration	12.5 (5.7)				
Harry et al., 2019[27]; United States; North America	Cross-sectional qualitative study; not reported	Paediatric rheumatology clinic or the hospital's active registry; convenience sampling (not reported)	*Overall sample (n = 22)*					
			Female	21 (95.5)	Systemic lupus erythematosus	22 (100)	Depression/anxiety	7 (31.8)
			Age					
			Adolescents (12-17 y)	16.1 (1.6)				
			Young adults (18-24 y)	20.2 (1.5)				
			Pain duration					
			Adolescents (12-17 y)	2.7 (2.5)				
			Young adults (18-24 y)	4.4 (2.6)				
			Included subset from overall sample (n = 12; 55%)					
			Female	11 (92)	Systemic lupus erythematosus	12 (100)	Depression/anxiety	2 (16.7)
			Age	20.2 (1.5)				
			Pain duration	4.4 (2.6)				
Jacobson et al., 2013[30]; United States; North America	Cross-sectional qualitative study; not reported	Outpatient paediatric rheumatology clinic; purposive stratified sampling (2010-2013)	*Overall sample (n = 34)*					
			Female	28 (82)	Juvenile idiopathic arthritis	18 (53)	Not reported	
			Age, mean (range)	13.8 (8-19)	Other non-disaggregated chronic pain conditions, including migraine (25%), chronic headache (19%), abdominal pain (13%), musculoskeletal pain (25%)	16 (47)		
			Pain duration	Not reported				
			Included subset from overall sample (n = 3; 9%)#					
			Female	Not reported	Juvenile idiopathic arthritis	3 (100)	Not reported	
			Age	Not reported				
			Pain duration	Not reported				

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Table 2 *(continued)*

Report citation; country; geographic region*	Study design; methodology†	Recruitment setting; sampling method (data collection year)	Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡		CMP diagnosis	n (%)	Mental health condition§	n (%)
Jiang et al., 2021[31]; Australia; Oceania	Cross-sectional qualitative study; not reported	Paediatric and adult hospitals; purposive sampling (2018-2019)	*Overall sample (n = 14)*‖					
			Female	8 (57)	Juvenile idiopathic arthritis	8 (57)	Not reported	
			Age	18.5 (2.1)	Systemic lupus erythematosus	3 (21)		
			Age at diagnosis, mean (range)	8 (2-15)	Familial Mediterranean fever	1 (7)		
					Panniculitis	1 (7)		
					Sterile multifocal osteomyelitis	1 (7)		
Knight et al., 2015[35],**; United States; North America	Cross-sectional qualitative study; not reported	Children's hospital rheumatology department; purposive and convenience sampling (2014-2015)	*Overall sample (n = 16)*‖					
			Female	13 (81)	Systemic lupus erythematosus	11 (69)	Depression	6 (38)
			Age	17.0 (3.6)	Mixed connective tissue disease	5 (31)	Suicidal ideation	5 (31)
			Pain duration, median (IQR)	3 (2.4-5.0)			Anxiety	8 (50)
Knight et al., 2016[34],**; United States; North America	Cross-sectional mixed-methods study; qualitative methodology not reported, quantitative survey	Children's hospital rheumatology department; purposive and convenience sampling (2014-2015)	*Overall sample (n = 16)*‖					
			Female	13 (81)	Systemic lupus erythematosus	11 (69)	History of depression and/or anxiety	9 (56)
			Age	17.0 (3.6)	Mixed connective tissue disease	5 (31)		
			Pain duration	3.8 (1.8)				
Lee et al., 2023[38]; United Kingdom; Europe	Cross-sectional qualitative study; not reported	Paediatric rheumatology centre in tertiary paediatric hospital; convenience sampling (2021)	*Overall sample (n = 26)*					
			Female	15 (58)	Juvenile idiopathic arthritis	16 (60)	Not reported	
			Age, median (IQR)	14.9 (11-16)	Chronic idiopathic pain syndrome	5 (20)		
			Pain duration, median (IQR)	3.9 (2-7)	Ehlers–Danlos syndrome	5 (20)		
			Included subset from overall sample (n = 9; 34%)					
			Female	7 (78)	Juvenile idiopathic arthritis	4 (44)	Not reported	
			Age	16.9 (0.9)	Chronic idiopathic pain syndrome	2 (22)		
			Pain duration	Not reported	Ehlers–Danlos syndrome	3 (33)		
Lin et al., 2021[40]; United States; North America	Cross-sectional qualitative study; not reported	Local rheumatology clinics and market research agency; purposive and convenience sampling (not reported)	*Overall sample (n = 31)*					
			Female	24 (77)	Rheumatoid arthritis	31 (100)	Not reported	
			Age	47.4 (14.4)				
			Pain duration	11.8 (8.7)				
			Included subset from overall sample (n = 3; 10%)					
			Female	2 (67)	Rheumatoid arthritis	3 (100)	Not reported	
			Age	21 (2.6)				
			Pain duration	4 (0)				

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Table 2 (*continued*)

Report citation; country; geographic region*	Study design; methodology†	Recruitment setting; sampling method (data collection year)	Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡		CMP diagnosis	n (%)	Mental health condition§	n (%)
Murray et al., 2022[49]; United States and Canada; North America	Longitudinal qualitative study; sequential mixed methods	Interdisciplinary paediatric pain clinics; purposive sampling (2018-2019)	*Overall sample (n = 17)*					
			Female	13 (77)	Chronic musculoskeletal conditions††	8 (47)	Depression (PHQ-9) [M (SD)]	9.59 (4.3)
			Age	21.2 (1.7)	Headache	1 (6)	Anxiety (GAD-7) total score, mean (SD)	8.53 (3.5)
			Pain duration	10.2 (4.4)	Abdominal	2 (12)		
					Neuropathic	2 (12)		
					Multiple types	4 (24)		
			Included subset from overall sample (n = 5; 29%)					
			Female	4 (80)	Chronic musculoskeletal pain	5 (100)	Not known	
			Age, range	21.4 (19-24)				
			Pain duration	Not reported				
Nilsson et al., 2011[52]; Sweden; Europe	Cross-sectional qualitative study; phenomenology	Orofacial pain clinic; convenience sampling (2005-2008)	*Overall sample (n = 21)*					
			Female	19 (90.5)	Temporomandibular pain	21 (100)	Not reported	
			Age, mean (range)	17.2 (15-19)				
			Pain duration	Not reported				
Nimbley et al., 2023[53]; United Kingdom; Europe	Cross-sectional mixed-methods study; realist perspective	Schools, community centres, social media, pain-related charities, online forums, newsletters; convenience sampling (not reported)	*Overall sample (n = 51)*					
			Female	45 (88)	Complex regional pain syndrome	51 (100)	Not reported	
			Age	19.8 (3.7)				
			Time since diagnosis	4.8 (3.0)				
Phuti et al., 2019[58]; South Africa; Africa	Cross-sectional qualitative study; phenomenology	Tertiary hospitals, lupus networks, and lupus clinics; purposive sampling (2016-2017)	*Overall sample (n = 25)*					
			Female	25 (100)	Systemic lupus erythematosus	25 (100)	Not reported	
			Age, mean (range)	30.9 (22-45)				
			Pain duration, mean (range)	≥5 (1-5)				
			Included subset from overall sample (n = 2; 8%)					
			Female	2 (100)	Systemic lupus erythematosus	2 (100)	Not reported	
			Age, mean (range)	23.5 (22-24)				
			Pain duration	Not reported				
Primholdt et al., 2017[60]; Denmark; Europe	Cross-sectional qualitative study; phenomenology	Rheumatology hospital department; purposive sampling (not reported)	*Overall sample (n = 5)*					
			Female	5 (100)	Ankylosing spondylitis	5 (100)	Not reported	
			Age, range	21-27				
			Pain duration	2.6				
			Included subset from overall sample (n = 2; 40%)					
			Female	2 (100)	Ankylosing spondylitis	2 (100)	Not reported	
			Age	22 (1.4)				
			Pain duration	Not reported				

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Table 2 (*continued*)

Report citation; country; geographic region*	Study design; methodology†	Recruitment setting; sampling method (data collection year)	Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡		CMP diagnosis	n (%)	Mental health condition§	n (%)
Slater et al., 2016[65]; Australia; Oceania	Cross-sectional qualitative study; grounded theory	Consumer organisations, clinical practices, mental health services; purposive sampling (2014-2015)	*Overall sample (n = 23)*					
			Female	20 (87)	Juvenile idiopathic arthritis	2 (8)	Comorbid mental health conditions (not disaggregated by condition)	14 (60.9)
			Age	20.8 (2.4)	Fibromyalgia	4 (17)		
			Pain duration, mean (range)	5.7 (0.4-20)	Neck/shoulders/back	1 (4)		
					Neck/back pain	1 (4)		
					Low back pain	1 (4)		
					Back pain	1 (4)		
					Low back/hip pain	1 (4)		
					Knee pain	2 (8)		
					Back pain/sciatica	2 (8)		
					Shoulder/back	1 (4)		
					Ankylosing spondylitis	1 (4)		
					Ankylosing spondylitis/OP	1 (4)		
					Mixed connective tissue disease	1 (4)		
					Hips/knees/back	1 (4)		
					Inflammatory arthritis/osteoarthritis	1 (4)		
					Scoliosis (back)	1 (4)		
Sorensen et al., 2017[71]; Norway; Europe	Cross-sectional qualitative study; qualitative exploratory design	Pain clinics; convenience sampling (not reported)	*Overall sample (n = 6)*					
			Female	4 (67)	Complex regional pain syndrome	4 (67)	Not reported	
			Age, median	16	Extreme muscle pain	2 (33)		
			Pain duration, range	1-5				
Tunnicliffe et al., 2016[76]; Australia; Oceania	Cross-sectional qualitative study; not reported	Tertiary care; purposive sampling (2013-2014)	*Overall sample (n = 26)*					
			Female	24 (92)	Systemic lupus erythematosus	26 (100)	Not reported	
			Age bands, n(%)					
			14-18 y	15 (58)				
			19-26 y	11 (42)				
			Pain duration, n(%)					
			0-3 y	10 (38)				
			4-6 y	6 (23)				
			7-9 y	7 (27)				
			10-12 y	3 (12)				

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Table 2 (*continued*)

Report citation; country; geographic region*	**Study design; methodology†**	**Recruitment setting; sampling method (data collection year)**	**Participant characteristics Female: n (%) Age y: mean (SD)‡ Pain duration y: Mean (SD)‡**		**CMP diagnosis**	**n (%)**	**Mental health condition§**	**n (%)**
Wernli et al., 2022[80]; Australia; Oceania	Longitudinal case series; mixed methods, interpretive description	Community, physiotherapy practices, workplaces; convenience sampling (2018)	*Overall sample (n = 12)*					
			Female	6 (50)	Low back pain	12 (100)	Depression, anxiety, posttraumatic stress disorder	
			Age	42.1 (17.3)				
			Pain duration	5.7 (4.3)				
			Included subset from overall sample (n = 1; 8%)					
			Female	1 (100)	Low back pain	1 (100)	Not reported	
			Age	22				
			Pain duration	6				
Zheng et al., 2021[85]; United States; North America	Cross-sectional qualitative study; qualitative description	Online; convenience sampling (2019-2020)	*Overall sample (n = 16)*					
			Female	12 (75)	Type 1 diabetes mellitus	6 (37.5)	Not reported	
			Age	22.3(2)	Cystic fibrosis	1 (6)		
			Pain duration	Not reported	Colitis	2 (12.5)		
					Crohn disease	1 (6)		
					Rheumatoid arthritis	1 (6)		
					Sickle cell disease	1 (6)		
					Systemic lupus erythematosus	1 (6)		
					Mast cell activation syndrome	1 (6)		
					Lyme disease	1 (6)		
					Inflammatory bowel disease	1 (6)		
			Included subset from overall sample (n = 2; 13%)					
			Female	2 (100)	Rheumatoid arthritis	1 (50)	Not reported	
			Age	23(8)	Systemic lupus erythematosus	1 (50)		
			Pain duration	Not reported				

* Geographic regions defined according to the World Bank (https://data.worldbank.org/country).

† Methodology reported as described in the report.

‡ Unless otherwise stated.

§ Participants in the cohort were considered to experience mental health impact where this was a sampling criterion, where patient-reported outcome measures evaluated mental wellbeing and the score(s) indicated a mental health condition, or from direct evidence noted in the participant's quotes.

‖ Overall sample refers only to the young people within this study. Data from parents/caregivers or health professionals were not extracted or reported.

¶ Demographic characteristics for the included subsample were not available for extraction (eg, due to lack of participant identifiers/information in data excerpts for the included sample) so are not reported here.

\# Only data relevant to a subsample with juvenile idiopathic arthritis were extracted from this report as the full sample did not meet the ≥75% CMP conditions required for inclusion. In addition, the musculoskeletal pain conditions in this sample were aggregated within a group called "chronic pain," so CMP could not be disaggregated from other pain conditions, such as neurological.

** Knight and colleagues used the same sample across their 2015 and 2016 reports, although the phenomena of interest differed.

†† Sample diagnostic characteristics were not described beyond "musculoskeletal pain."

IQR, interquartile range; n, sample size; SD, standard deviation.

exclusion criteria, recruitment method, sampling method, data collection and analysis framework, and personnel; researcher positionality related to data collection and analysis; and sample characteristics including size, sex/gender profiles, pain and mental health characteristics, and other comorbid conditions, as reported. For some reports, only a subset of disaggregated data included in a report met the inclusion criteria for the review (eg, a subset by age or CMP condition). In these circumstances, only the subset of data was extracted for the meta-synthesis. In cases where disaggregated data were provided but participant identifiers (eg, participant 1, participant 2, etc.) were not provided, the data were extracted based on the age and diagnosis information provided; however, in these cases, we were unable to determine participant characteristics as the individual participants contributing to the quotes could not be confirmed. First-order data (direct quotes from the primary study participants), and second-order data (themes, subthemes, and interpretations of these by authors of included articles) were extracted. Only data relevant to the inclusion criteria were systematically extracted.

2.5. Quality and trustworthiness appraisal

The methodological quality of each included study was appraised independently by pairs of reviewers from a pool of 4 (A.M.B., N.R.K., J.C., and S.R.), with arbitration by a third reviewer to resolve discordances, where necessary (H.S.). Within this pool, no reviewer appraised a report (or arbitrated) on which they were a coauthor. The Joanna Briggs Institute (JBI) Quality Appraisal Tools for Qualitative Studies or Analytical Cross-sectional Studies were used to assess the trustworthiness of the included reports.[42] No studies were excluded based on quality and we did not undertake a sensitivity analysis based on quality.

2.6. Data analysis and synthesis

Extracted data were meta-synthesised using a staged approach of thematic synthesis aligned to the approach described by Thomas and Harden,[73] and led by one author (N.R.K.) (Supplementary file 7, http://links.lww.com/PAIN/C135). This staged process of thematic synthesis comprised 5 stages: (1) coding; (2) development of categories; (3) development of themes; (4) description of findings; and (5) interpretation of findings. Stages 4 and 5 are not described by Thomas and Harden[73] but were included as part of the analytic process in this QES to facilitate clear recommendations for clinical practice and health service re-design. Stage 4 was also included to align with the terminology and requirements for the GRADE-Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) process to assess confidence in each meta-synthesis finding (see section 2.7). While stages of this synthesis are presented linearly in Supplementary file 7, http://links.lww.com/PAIN/C135, analysis was iterative in nature, involving constant back and forth between the raw data and 5 stages of analysis, including consultation with other reviewers (S.R., A.M.B., H.S.). Throughout the process of analysis, the authorship team were sensitive to how their findings and interpretations were generated and aligned with reflexive practice (Supplementary file 8, http://links.lww.com/PAIN/C135). Consistent with our protocol, we did not perform subgroup analyses, eg, by CMP type. While we adopted a transdiagnostic approach for CMP and mental health conditions in synthesising findings, we identified within findings where unique context was relevant to a subpopulation. Furthermore, confidence in the transferability of context across primary data was considered and reported as part of the GRADE-CERQual assessment (see section 2.7).

2.7. Assessment of confidence in synthesis

Confidence in each finding was assessed using the GRADE-CERQual process across 4 domains: methodological limitations, coherence, adequacy of data, and relevance, resulting in an overall level of confidence for each finding (high, moderate, low, or very low confidence).[39] All review findings were considered "high confidence" at the start of appraisal and then downgraded by one or more levels if there were concerns regarding any of the CERQual domains.[39] Two reviewers (N.R.K., S.R.) evaluated confidence though discussions, with re-review by A.M.B.

3. Results

From a search yield of 9460 unique citations, 108 and 81 citations were identified from databases and other sources, respectively, for full-text review. A total of 22 studies in 23 reports were included for meta-synthesis.[5,15,18,22,25–27,30,31,34,35,38,40,49,52,53,58,60,65,71,76,80,85] Excluded studies and reasons for exclusion are summarised in Supplementary file 9, http://links.lww.com/PAIN/C135. Although 2 reports were based on a single study,[34,35] given the focus of the data presented in each report was unique, we treated the reports as separate data sources. **Figure 1** details the study selection process for both research questions.

3.1. Study participants

Characteristics of the 23 included reports are summarised in **Table 2**. We extracted a subset of data from 13 (57%) reports (**Table 2**).[15,18,25–27,30,38,40,49,58,60,80,85] Owing to reporting variability and limitations, precise estimates of demographic characteristics could not be derived for sample size, age, and sex for all included reports. Of the 22 reports that detailed the sample size of the included cohorts, 239 young people (82% women) were represented in this QES (one report did not provide sample size information[18]). Of the 8 reports for which mean age was available, this ranged from 16 to 20 years,[5,18,31,34,35,52,53,65,71,76] Similarly, mean ages ranged from 17 to 24 years when a subset of data was extracted from 10 other reports[15,25–27,38,40,49,58,60,85]; see **Table 2** for further information.

Across the 23 included reports, young people had diverse CMP conditions, although one report[30] did not disaggregate participants by CMP diagnosis. Nineteen primary or secondary CMP conditions were reported and the number of participants with each included: systemic lupus erythematosus (SLE) ($n = 63$)[5,18,25,27,31,34,35,59,76,85]; complex regional pain syndrome ($n = 58$)[15,53,71]; joint hypermobility syndromes ($n = 4$)[15,38]; fibromyalgia ($n = 5$)[15,22,65]; axial and peripheral arthritis conditions including juvenile idiopathic arthritis (JIA), rheumatoid arthritis, ankylosing spondylitis, inflammatory arthritis, and osteoarthritis ($n = 40$)[18,26,30,31,38,40,60,65,85]; mixed connective tissue disease ($n = 6$)[34,35,38,65] chronic idiopathic pain syndrome ($n = 2$),[38] nonspecified musculoskeletal pain ($n = 5$),[49] temporomandibular disorder ($n = 21$),[52] back pain presentations excluding inflammatory spondlyoarthritis ($n = 8$),[65] knee pain ($n = 2$),[65] osteoporosis ($n = 1$),[65] hips/knees/back pain ($n = 1$),[65] and extreme muscle pain ($n = 2$).[71] **Table 2** provides detailed descriptions of the clinical characteristics of the included cohorts, as reported in the included studies.

Reports described research conducted in the United States,[5,18,22,25,27,29,30,34,35,40,49,85] Australia,[31,65,76,80] the United Kingdom,[15,26,38,53] Canada,[18,49] Sweden,[52] South Africa,[58] and Norway,[71] Denmark.[60,71] Participants were recruited from hospitals,[26,31,34,35,58,60,76] schools,[15,53] patient organisations,[18,58,65] hospital clinics,[5,25,27,30] community clinics,[15,40,49,52,53,65,71,80] a market research agency,[40] workplaces,[80] pain-related charities,[53] newsletters,[53] and through online channels.[15,53,85]

3.2. Themes and findings

Four themes were derived that described the lived experience of young people living with coexisting CMP and mental health conditions (Research question 1), underpinned by 9 discrete findings. Three themes described care experiences/preferences (Research question 2), underpinned by 8 discrete findings. The structure of findings is summarised in **Table 3**, supported by a Summary of Findings table (**Table 4**). Across the 17 findings, 9 (53%) were graded as moderate confidence, 5 (29.4%) as low confidence, and 3 (17.6%) as very low confidence. Supplementary File 10, http://links.lww.com/PAIN/C135 summarises the detailed ratings by GRADE-CERQual domain.

3.3. Research question 1: What are the lived physical, psychological, and social experiences of young people (16-24 years) experiencing CMP and mental health conditions?

Theme 1.1: Young people described a two-way relationship between their experiences of CMP and mental health conditions

Young people consistently described the interconnectedness of CMP and mental health, manifesting as a negative impact on their overall wellbeing, ie, a whole-of-person impact. Young people also identified a two-way relationship between CMP and mental health conditions, explaining how CMP can influence their emotions and cognitions, and conversely how emotions and cognitions can affect their experience of CMP.

Table 3

Structure of synthesis findings, organised by research question, inductively derived themes, and the findings underpinning each theme.

Research question 1: What are the lived physical, psychological, and social experiences of young people (16-24 y) experiencing CMP and mental health conditions?	
Theme 1.1: Young people described a two-way relationship between their experiences of CMP and mental health conditions	Finding 1.1.1: CMP negatively influences young people's mental health Finding 1.1.2: Mental health negatively influences young people's experiences of CMP
Theme 1.2: Impact of coexisting CMP and mental health conditions on young people as a whole	Finding 1.2.1: Young people's social engagement and development of identity are affected by interacting CMP and mental health conditions Finding 1.2.2: Young people living with CMP and mental health conditions experience stigma and/or invalidation, and the decision to disclose their condition provokes anxiety and fear Finding 1.2.3: Interference with physical function and body changes associated with CMP impacts on young people's mental health
Theme 1.3: Young people's uncertainty about their future lives with CMP negatively impacts their mental health	Finding 1.3.1: Worries about a future with CMP can have an enduring impact on young people's mental health Finding 1.3.2: Uncertainty around treatment, medication, and care for CMP compounds the impact on young people's mental health
Theme 1.4: Young people's experience of coping with CMP and coexisting mental health conditions	Finding 1.4.1: Attempting to cope with coexisting CMP and mental health conditions takes an emotional toll on young people Finding 1.4.2: The unpredictable nature of coexisting CMP and mental health conditions negatively affects young people's sense of control
Research question 2: What are the care experiences, preferences, and/or priorities of young people (16-24 y) experiencing CMP and mental health conditions?	
Theme 2.1: Young people's experiences and preferences related to their interactions with health services	Finding 2.1.1: Navigating fragmented health care was experienced as challenging by young people living with coexisting CMP and mental health conditions Finding 2.1.2: Young people living with CMP and coexisting mental health conditions can feel empowered or disempowered during the transition from paediatric to adult care services
Theme 2.2: Young people's experiences and preferences related to diagnosis and accessing integrated and flexible care	Finding 2.2.1: The diagnostic process for CMP can have a negative impact on young peoples' mental health Finding 2.2.2: Young people with coexisting pain and mental health conditions experience challenges accessing mental health support Finding 2.2.3: Young people with coexisting pain and mental health conditions value flexible care structures, age-appropriate and accessible resources (including digital technologies), and opportunities to engage with peers
Theme 2.3: Young people's experiences and preferences related to interactions with health professionals at the point of care	Finding 2.3.1: Young people who felt dismissed, invalidated, or unsupported by healthcare professionals experienced negative impacts on their mental health Finding 2.3.2: Young people with coexisting pain and mental health conditions value support to manage their complex emotions and need to feel comfortable, validated, and understood by health professionals Finding 2.3.3: The importance of strong therapeutic relationships, safe consultation environments, and individualised care for young people living with coexisting CPM and mental health conditions

Table 4

Summary of findings and overall GRADE-Confidence in the Evidence from Reviews of Qualitative Research assessments.

Summarised finding	GRADE-CERQual overall confidence assessment	Explanation of GRADE-CERQual assessment	References
Research question 1: What are the lived physical, psychological, and social experiences of young people (16-24 y) experiencing CMP and mental health conditions?			
Theme 1.1: Young people described a two-way relationship between their experiences of CMP and mental health conditions			
1.1.1 Pain was described as having a negative impact on young people's mental health. Young people described how pain could negatively impact on their emotions and cognitions, including anxiety, frustration, fear, and depression, and cause worry and rumination.	Moderate confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	11 reports Bitencourt et al., 2021[5]; Corser et al., 2023[15]; Hanson et al., 2018[26]; Jacobson et al., 2013[30]; Lee et al., 2023[38]; Lin et al., 2021[40]; Nilsson et al., 2011[52]; Nimbley et al., 2023[53]; Slater et al., 2016[65]; Sorensen et al., 2017[71]; Wernli et al., 2022.[80]
1.1.2 Some young people described their mental health as influencing their experience of pain. Emotions such as low mood or anxiety could worsen the experience of pain, and negative cognitions would trigger the onset of pain.	Low confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; serious concerns regarding adequacy; minor concerns regarding relevance.	4 reports Knight et al., 2015[35]; Lee et al., 2023[38]; Nilsson et al., 2011[52]; Slater et al., 2016.[65]
Theme 1.2: Impact of coexisting CMP and mental health conditions on young people as a whole			
1.2.1 Young people described experiencing isolation and feeling different because of their CMP condition. Young people explained difficulties socially connecting due to being excluded or needing to cancel plans due to pain flares. Socially connecting was considered an important coping strategy for young people. Difficulties with social participation as well as the physical limitations of CMP resulted in challenges to their sense of identity and engagement in identity-defining activities.	Low confidence	Moderate concerns regarding methodological limitations; serious concerns regarding coherence; minor concerns regarding adequacy; minor concerns regarding relevance.	12 reports Corser et al., 2023[15]; Harry et al., 2019[27]; Jiang et al., 2021[31]; Knight et al., 2015[35]; Knight et al., 2016[34]; Lin et al., 2021[40]; Nimbley et al., 2023[53]; Phuti et al., 2019[58]; Primholdt et al., 2017[60]; Slater et al., 2016[65]; Sørensen et al., 2017[71]; Zheng et al., 2021.[85]
1.2.2 Young people often chose to keep their pain condition a secret or to "mask" it due to perceptions of being different, stigmatised, or invalidated. For many young people, the decision to disclose their CMP condition was met with significant worry and felt like a double-edged sword: others knowing, may have been helpful, but there was fear they would be judged.	Moderate confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; moderate concerns regarding adequacy; minor concerns about relevance.	9 reports Corser et al., 2023[15]; Hale et al., 2015[25]; Hanson et al., 2018[26]; Harry et al., 2019[27]; Lin et al., 2021[40]; Nimbley et al., 2023[53]; Phuti et al., 2019[58]; Slater et al., 2016[65]; Tunnicliffe et al., 2016.[76]
1.2.3 Physical limitations of living with CMP meant some young people experienced difficulties with study or work. Symptoms of fatigue meant keeping up at school could be difficult. Some physical difficulties were reported as embarrassing for young people, while others who were taking medication that resulted in physical changes, struggled with their appearance.	Very low confidence	Moderate concerns regarding methodological limitations; serious concerns regarding coherence; serious concerns regarding adequacy; serious concerns regarding relevance.	6 reports Hale et al., 2015[25]; Knight et al., 2016[34]; Nilsson et al., 2011[52]; Primholdt et al., 2017[60]; Sørensen et al., 2017[71]; Zheng et al., 2021.[85]

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Table 4 (*continued*)

Summarised finding	GRADE-CERQual overall confidence assessment	Explanation of GRADE-CERQual assessment	References
Theme 1.3: Young people's uncertainty about their future lives with CMP negatively impacts their mental health			
1.3.1 Many young people described the feeling of a life-long CMP condition as daunting, tiring, and disappointing. This finding related to those who had received a specific CMP diagnosis. Young people worried about how they were going to manage their CMP condition into older age. The prospect of a long-term condition was associated with a feeling of uncertainty about whether they could reach their goals, work full-time, or have a relationship or family.	Moderate confidence	Moderate concerns regarding methodological limitations; moderate concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	10 reports Hanson et al., 2018[26]; Harry et al., 2019[27]; Jiang et al., 2021[31]; Lee et al., 2023[38]; Lin et al., 2021[40]; Nilsson et al., 2011[52]; Primholdt et al., 2017[60]; Slater et al., 2016[65]; Sørensen et al., 2017[71]; Tunnicliffe et al., 2016.[76]
1.3.2 Young people expressed worry and anxiety related to making treatment decisions, especially for young people with nonspecific CMP. Their concerns related to unknowingly worsening their condition with an incorrect treatment decision, or an inability to access the right treatments. Navigating care in this way felt like a large weight and responsibility for young people. Young people who required medication for their CMP expressed concern about long-term reliance on medication.	Low confidence	Serious concerns regarding methodological limitations; minor concerns regarding coherence; serious concerns regarding adequacy; serious concerns regarding relevance.	5 reports Hale et al., 2015[25]; Jiang et al., 2021[31]; Knight et al., 2016[34]; Lee et al., 2023[38]; Slater et al. 2016[65]
Theme 1.4: Young people's experience of coping with CMP and coexisting mental health conditions			
1.4.1 Coping with CMP and coexisting mental health conditions was considered challenging. Young people described a range of different approaches to coping. They described how difficulties coping emotionally or through pain control strategies resulted in negative impacts on their mental wellbeing.	Low confidence	Minor concerns regarding methodological limitations; moderate concerns regarding coherence; serious concerns regarding adequacy; minor concerns regarding relevance.	11 reports Hale et al., 2015[25]; Jiang et al., 2021[31]; Knight et al., 2016[34]; Lee et al., 2023[38]; Lin et al., 2021[40]; Nilsson et al., 2011[52]; Nimbley et al., 2023[53]; Slater et al., 2016[65]; Sørensen et al., 2017[71]; Tunnicliffe et al., 2026[76]; Wernli et al., 2022.[80]
1.4.2 The unpredictability of both pain and mental health experiences was a challenge for young people. Young people could feel out of control, not knowing when symptoms would flare. Some young people felt powerless over their pain.	Moderate confidence	Moderate concerns regarding methodological limitations; moderate concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	5 reports Corser et al., 2023[15]; Knight et al., 2015[35]; Nilsson et al., 2011[52]; Sørensen et al., 2017[71]; Zheng et al., 2021.[85]
Research question 2: What are the care experiences, preferences, and/or priorities of young people (16-24 y) experiencing CMP and mental health conditions?			
Theme 2.1: Young people's experiences and preferences related to their interactions with health services			
2.1.1 Young people's experience of the healthcare services was fragmented and they had difficulty finding support and appropriate information and resources they needed. Young people desired a more integrated healthcare system.	Moderate confidence	Moderate concerns regarding methodological limitations; moderate concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	3 reports Knight et al., 2016[34]; Lee et al., 2023[38]; Slater et al., 2016.[65]
2.1.2 The experience of transitioning from paediatric to adult services was challenging and felt like being "thrown in the deep end". Young people struggled with a loss of their relationship with paediatric health professionals and experienced feelings of hopelessness, being overwhelmed, and wanting to give up. However, some young people felt empowered through transitioning to adult care.	Moderate confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; minor concerns regarding adequacy; moderate concerns regarding relevance.	4 reports Bitencourt et al., 2021[5]; Jiang et al., 2021[31]; Murray et al., 2022[49]; Tunnicliffe et al., 2016.[76]

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Table 4 (*continued*)

Summarised finding	GRADE-CERQual overall confidence assessment	Explanation of GRADE-CERQual assessment	References
Theme 2.2: Young people's experiences and preferences related to diagnosis and accessing integrated and flexible care			
2.2.1 The diagnostic process was considered a difficult time. Some young people experienced a delay in receiving a diagnosis due to perceived dismissal by healthcare professionals. While a diagnosis could result in a sense of relief, it was also met with stress and worry, and fear that the diagnosis could be dangerous. Repeated investigations also provoked significant fear and worry.	Moderate confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; moderate concerns regarding adequacy; moderate concerns regarding relevance.	5 reports Knight et al., 2016[34]; Lee et al., 2023[38]; Primholdt et al., 2017[60]; Sørensen et al., 2017[71]; Tunnicliffe et al., 2016.[76]
2.2.2 Young people described barriers to mental health support, including access and affordability. Some young people also described reluctance from their doctor to refer them to a mental health professional.	Very low confidence	Serious concerns regarding methodological limitations; serious concerns regarding coherence; serious concerns regarding adequacy; serious concerns regarding relevance.	2 reports Knight et al., 2015[35]; Lee et al., 2023.[38]
2.2.3 Young people wanted flexible care to work around their lives, including rapid access to disease-modifying medication for young people experiencing autoimmune inflammatory conditions, and the ability to combine appointments to minimise clinical visits. Age-appropriate resources and education, as well as digital solutions and opportunities to engage with other young people with CMP, were desired.	Moderate confidence	Moderate concerns regarding methodological limitations; minor concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	6 reports Fawole et al., 2021[18]; Goldenberg et al., 2013[22]; Hanson et al., 2018[26]; Harry et al., 2019[27]; Slater et al., 2016[65]; Tunnicliffe et al., 2016.[76]
Theme 2.3: Young people's experiences and preferences related to interactions with health professionals at the point of care			
2.3.1 Young people often felt dismissed, invalidated, and unsupported by health professionals. They described frustrations with healthcare professionals who could not help them or lacked the requisite knowledge about their condition.	Moderate confidence	Moderate concerns regarding methodological limitations; moderate concerns regarding coherence; moderate concerns regarding adequacy; minor concerns regarding relevance.	4 reports Corser et al., 2023[15]; Hanson et al., 2018[26]; Lee et al., 2023[38]; Slater et al., 2016.[65]
2.3.2 Mental health support could have been helpful for young people in processing and making sense of complex emotions associated with their CMP. However, some young people experienced discomfort with mental health conversations or did not feel mental health professionals understood the impact of pain on their mental health.	Very low confidence	Serious concerns regarding methodological limitations; serious concerns regarding coherence; moderate concerns regarding adequacy; serious concerns regarding relevance.	2 reports Fawole et al., 2021[18]; Knight et al., 2015.[35]
2.3.3 Young people valued strong therapeutic relationships and individualized care. They wanted education about their condition, as well as education on the medications they were using. Young people desired an understanding about their pain and ways they could self-manage.	Low confidence	Moderate concerns regarding methodological limitations; serious concerns regarding coherence; minor concerns regarding adequacy; minor concerns regarding relevance.	5 reports Harry et al., 2019[27]; Knight et al., 2015[35]; Lee et al., 2023[38]; Slater et al., 2016[65]; Tunnicliffe et al., 2016.[76]

Results are organised by research question, inductively derived themes, and the findings underpinning each theme.

Finding 1.1.1: CMP negatively influences young people's mental health (moderate confidence; 11 reports)

Young people described a directional relationship between CMP and mental health conditions, where the experience of CMP exacerbated their mental health conditions, with pain influencing their emotions and cognitions.[15,26,30,38,40,52,65,71,80] For example, experiencing CMP was described by some young people as resulting in feelings of anxiety, frustration, irritability, despondency, and depression[5,26,30,40,52,53,65] It was described by one participant as a "…black cloud over me."[38] For some young people, the emotional burden (ie, distress and despair) associated with their CMP experience was more debilitating than the pain itself.[38,71] Cognitively, participants described their pain as taking over their thoughts, leading to rumination[30,52]; and indicating that they "…can't shut it out."[52] For some, their CMP was associated with fear, including fear of the pain itself, or a pain flare,[71] or fear of movements as potential threats that could cause pain or exacerbate their pain.[80]

Finding 1.1.2: Mental health negatively influences young people's experiences of CMP (low confidence; 4 reports)

Young people also described the relationship between pain and coexisting mental health conditions in the other direction, whereby emotions and cognitions could impact their experience of pain.[35,38,52,65] Some young people explained that if they let themselves think about pain, this heightened their awareness of pain[38,52]; "…it's there if I think about it."[52] In addition, young people described how their pain could worsen when they experienced emotional upset, anxiety, or low mood.[65]

Theme 1.2: Impact of coexisting CMP and mental health conditions on young people as a whole person

There was a complex relationship between pain, mental health, and young people's sense of identity and self, which had broader implications for their social worlds, including their families, friendships, relationships, and ability to work, study, or engage in physical activities.

Finding 1.2.1: Young people's social engagement and development of identity are affected by interacting CMP and mental health conditions (low confidence; 12 reports)

Young people experienced various challenges to social engagement, including feelings of being different and isolated.[15,27,34,40,53,58,60,65,71] Living with pain also meant their ability to engage socially and create friendships was limited, in part due to being excluded from social events.[31] Threats to social participation and identity-defining activities resulted in resentment toward their CMP condition, challenged their identity, and compounded their mental health conditions, expressed as feeling down or frustrated.[34,60] Physical function impairments meant that their participation in activities that bring them meaning and define their sense of self was limited.[15,34] This extended to some young people describing the impacts of coexisting CMP and mental health conditions as limiting their opportunities and ability to find a sense of purpose.[15] Young people explained how experiencing pain flares often meant they would withdraw from social engagements—cancelling plans, which could further strain friendships, or friendships could fade away.[40,85] Conversely, symptom stability enabled young people to more easily engage socially.[31] Some participants considered the ability to remain socially active to make up for the physical limitations associated with their conditions, making socialisation an important aspect of their overall wellbeing.[35]

Finding 1.2.2: Young people with CMP and mental health conditions experience stigma and/or invalidation, and the decision to disclose their condition provokes anxiety and fear (moderate confidence; 9 reports)

Many young people chose to keep their CMP condition a secret, or to "mask"[15,25] it, for fear of being perceived as different. Young people often described feeling stigmatised and/or invalidated because of their CMP condition.[15,40,53,65] Friendships could be strained due to a lack of understanding about their condition,[40] while young people also described feeling like a burden to their families.[15] The decision to disclose their condition to others provoked anxiety, which felt like a double-edged sword, adding further mental health burden: in some ways, it may be easier when others knew, but there was fear and uncertainty about how others would judge them.[15,26,27,65] Where other people knew about their condition, young people described frustration at being treated as different, furthering the impact of the coexisting mental health conditions they were experiencing.[76] Some young people described experiencing prejudice and lack of understanding at what they described as an "undercover"[58] or "invisible"[40,58,65] illness.

Finding 1.2.3: Interference with physical function and body changes associated with CMP impacts on young people's mental health (very low confidence; 6 reports)

Young people described difficulties with working or studying,[52,60] where losing their ability to complete physical tasks further impacted their mental health, leaving them embarrassed and frustrated, wondering why they could not just "suck it up."[60] The experience of CMP also impacted young people's ability to concentrate and exacerbated their levels of fatigue, causing difficulties with educational performance, attendance, and completing school tasks.[52,71] Young people with temporomandibular pain described the vicious cycle between physical function problems (such as eating and yawning) and the additional impact on their mental health, including feeling tired, irritated and down, or embarrassed and awkward.[52] Young people who experienced pain secondary to chronic conditions such as SLE that resulted in visible physical changes, or who took medications that caused weight gain, hair loss, or acne, struggled with their physical appearance and described the additional impact this had on their mental health, including feelings of embarrassment and shame.[25,34,85]

Theme 1.3: Young people's uncertainty about their future lives with CMP negatively impacts their mental health

The uncertainty that young people living with CMP identified about their future, whether they were making the correct treatment decisions, and if they could still achieve their goals, impacted their mental health.

Finding 1.3.1: Worries about a future with CMP can have an enduring impact on young people's mental health (moderate confidence; 10 reports)

Young people's expectation that their condition may not improve, that they were potentially stuck with this for life, had an enduring impact on their mental health, including feeling daunted, tired, and disappointed, especially for those who had received a specific diagnosis, such as ankylosing spondylitis.[38,52,60,65] Many young people expressed concerns about how they would manage as they got older.[38,65,76] They expressed a sense of uncertainty about what their pain condition meant for their future and what the future would bring, including the prospect of condition progression.[65,76] Some expressed concern about their capacity to succeed in life while living with CMP, including their ability to study and attend university.[31,71] Others worried that employers may not be willing to offer them positions,[26,27,76] and that they would be unable to maintain full-time work or reach their career goals.[31,40,76] For some, their pain condition was linked to worries about achieving autonomous goals, such as the capacity to live independently and have a relationship or family.[27] Young women who had autoimmune conditions such as SLE, or who were on long-term medications, were concerned about their ability to have children—both through fear of inheritance of their condition, or medication harming their child.[27,76]

Finding 1.3.2: Uncertainty around treatment, medication, and care for CMP compounds the impact on young people's mental health (low confidence; 5 reports)

One report identified worry and anxiety related to making the right treatment decisions could intensify impacts to their mental health. This was especially evident among those young people who perceived diagnostic uncertainty as it related to nonspecific CMP where clear treatment pathways were absent.[65] There was concern that an already debilitating pain condition could worsen without access to the right treatment, at the right time, or through unknowingly receiving unhelpful treatments.[65] The ability to identify and access the right care was perceived as a big responsibility, due to the implications for their future lives.[65] For some, the persisting uncertainty about treatment and diagnosis led to feelings of depression, or the persisting worry (rumination) becoming more debilitating than their pain.[65] Young people who required long-term medication for their CMP (eg, medicines for SLE) identified varied emotions and mental health impacts. Although they were aware of the importance of their medication(s), young people were also frustrated and disconcerted with a long-term reliance on medication,[31,34,38] were worried about the long-term harms of the medication(s),[25,31] and nervous that the therapeutic effect would decline over time.[38]

Theme 1.4: Young people's experience of coping with CMP and coexisting mental health conditions

Young people described coping with their symptoms and functional limitations in different ways. Findings described the interaction between coping mechanisms for coexisting CMP and mental health conditions, suggesting a bidirectional relationship whereby their ability to cope with pain affects their emotions and cognitions, and emotions and cognitions can impact their ability to cope with pain. The findings extend to how lacking helpful coping skills or adopting unhelpful coping strategies can leave them feeling out of control, magnifying negative mental health impacts already associated with living with CMP and mental health conditions.

Finding 1.4.1: Attempting to cope with coexisting CMP and mental health conditions takes an emotional toll on young people (low confidence; 11 reports)

Having to cope with the emotional toll associated with their CMP condition, was described as stressful[34] and challenging by young people.[53,65] They expressed challenges coping with difficult emotions associated with their CMP condition, resulting in them feeling sad and isolated, and putting on a happy front, but feeling low internally.[25,34] Young people described using a range of behavioural and cognitive coping strategies to manage CMP and mental health conditions, such as exercise[65] and adopting relaxed movements and postures,[80] seeking social support,[65,76] trying to remain positive and optimistic,[71] using distraction,[38] not allowing their pain to become bothersome,[38,71] accepting their pain,[31,38,40,52] viewing their pain as a challenge that can be overcome,[76] or holding on to hope that things will improve.[52] Some described coping behaviours as crying, shouting, and punching walls[71] and internalising the pain or "knuckling down."[52] Coping responses had varying benefits and did not always improve their pain experience. For example, some described losing all hope when their condition was perceived as an immovable fixture, and this could not be reconceptualised.[52,53]

Finding 1.4.2: The unpredictable nature of coexisting pain and mental health conditions negatively affected young people's sense of control (moderate confidence; 5 reports)

The unpredictability of both CMP and mental health conditions presented a challenge to young people, with the co-occurrence of these described as leading to them feeling out of control.[15,52,85] For example, young people were often uncertain when a pain flare would occur, resulting in a state of hypervigilance—constantly on the lookout for potential threats, which was mentally exhausting.[15,71] Young people described losing trust in their ability to manage their wellbeing (pain and mental health) due to the unpredictability of these conditions.[15] Some explained how the symptoms felt external to them, as though what was happening was experienced outside of their bodies, beyond their abilities to manage[15] They described living in a dissociative state, where both pain and mental health conditions controlled their actions, rather than themselves being in control.[15] Other participants described feeling powerless over their pain, as though pain was taking over their lives – limiting their ability to attend school.[85] Conversely, for some, gaining of control and self-efficacy resulted in improved mental health and a stronger sense of self.[35]

3.4. Research question 2: What are the care experiences, preferences, and/or priorities of young people (16-24 years) experiencing CMP and mental health conditions?

Theme 2.1: Young people's experiences and preferences related to their interactions with health services

For young people living with coexisting CMP and mental health conditions, challenges in navigating various aspects of health systems and accessing coordinated, integrated, and age-relevant care represented a significant burden and could exacerbate their pain and mental health.

Finding 2.1.1: Navigating fragmented health care was experienced as challenging by young people with coexisting CMP and mental health conditions (moderate confidence; 3 reports)

Young people described their experiences of scattered and fragmented health care, including difficulty accessing an affordable family physician who could coordinate their care, or finding appropriate and relevant resources for their age and condition.[65] Young people indicated a desire for more integrated health services, including better interaction between different health professionals to reduce fragmentation and improve care coordination.[65] Some explained they received conflicting information from different practitioners,[34,38] while others struggled with the responsibility and requisite skills needed to coordinate their own care, including scheduling tests, procedures, and appointments across different providers.[34] Young people explained how communicating with different health professionals was challenging, especially when the young people were uncertain about the different roles of each of the providers.[34,65]

Finding 2.1.2: Young people living with CMP and coexisting mental health conditions can feel empowered or disempowered during the transition from paediatric to adult care services (moderate confidence; 4 reports)

For young people making the transition from paediatric to adult pain care services, many felt they were unsupported and struggled with the new structure and expectations of the adult service.[31,49,76] This included losing a strong and trusted relationship with their paediatric care team, struggling to forge these similar relationships in the adult service,[5,31,49] and feeling "dumped" and "cut off" by their paediatric providers.[49] Compared with their paediatric care, adult services were perceived as rigid, which was intimidating and scary for the younger cohorts (those aged 16-18 years experiencing care transition).[31] Transition was often perceived as an unstable period, which could jeopardise the stability in their condition management.[31] Young people were frustrated at having to reiterate their medical history to new health care professionals, making them feel insignificant.[31] The emotions associated with this care transition period were described as overwhelming, feeling out of control, hopeless, and wanting to give up.[5,49] There was fear of the unknown and fear of creating new therapeutic relationships.[5,31] The notion of "starting over" was emotionally taxing for some, on top of living with the daily experiences of chronic pain.[49] However, for some young people, the transition marked a positive period in their lives where they felt stronger and more confident.[5] Some described the transition process as empowering, offering an opportunity to start taking control and living a meaningful life with pain.[49] Young people also described factors that made navigating adult services easier.[31] These included adult providers taking interest in their personal goals, having guidance and support from multiple healthcare professionals, meeting with adult providers before transition, ensuring a clear transfer of documents and communication between adult and paediatric services, and having social support.[31]

Theme 2.2: Young people's experiences and preferences related to diagnosis and accessing integrated and flexible care

Young people experienced challenges and further emotional impacts when seeking/accessing holistic, integrated care services. These challenges and impacts are related to a difficult diagnostic process, a desire for attention to their mental health, and the desire for flexible, age-appropriate care.

Finding 2.2.1: The diagnostic process for CMP can have a negative impact on young people's mental health (moderate confidence; 5 reports)

The pathway to receive a diagnosis, particularly for young people with specific conditions (eg, SLE and JIA), was described as a difficult time.[34,60,76] Some experienced a delay in diagnosis because of what they perceived as continued dismissal from their health professionals.[76] While receiving a diagnosis could be relieving at times, and validation of their pain experience as being "real"[60] could be helpful; the diagnosis could also provoke stress, confusion, anger, and guilt. These emotions associated with a diagnosis, elevated fear that their diagnosis could be dangerous,[71] heightening the negative impact on their mental health.[34,60] The lead-up to receiving a diagnosis was also described as an intense period of uncertainty, worry, and insecurity, further impacting their mental health.[60] Undertaking diagnostic investigations could often cause despair in young people, especially when a test revealed "nothing,"[71] or resulted in a young person experiencing more fear and uncertainty of "finding something else wrong."[38] Similarly, inconsistent or contradictory explanations about their pain from different healthcare professionals resulted in increased anxiety, uncertainty, and fear for young people.[71]

Finding 2.2.2: Young people with coexisting pain and mental health conditions experienced challenges accessing mental health support (very low confidence; 2 reports)

Many barriers to mental health support were raised by young people, including the lack of availability and accessibility of care due to the need to travel and affordability (ie, high costs).[35] Some found it easier to engage with a school counsellor, where available.[35] Young people also described difficulty in receiving a referral from their doctor for mental health services, being given the impression their mental health would just improve with time as their pain condition was treated.[35,38]

Finding 2.2.3: Young people with coexisting pain and mental health conditions value flexible care structures, age-appropriate and accessible resources (including digital technologies), and opportunities to engage with peers (moderate confidence; 6 reports)

Young people value flexible care, to work around the demands of their young lives—especially during periods such as exams or starting a new job.[26] This included rapid access to disease-modifying medications for young people with autoimmune conditions and the option to combine appointments to minimise visits.[26] Young people also described a lack of age-appropriate resources and made clear the need for information that is developmentally appropriate and relevant to their circumstances,[26,76] including less "science-y" talk.[27] Some indicated that digital technologies, such as apps and websites for both information on pain and mental health management are appropriate ways to receive trustworthy information about their conditions.[18,65] Young people also consistently outlined a desire to engage with other young people who have a shared lived experience of CMP, so they can feel understood and validated and gain advice and strategies to self-manage.[18,22,26]

Theme 2.3: Young people's experiences and preferences related to interactions with health professionals at the point of care

Young people valued individualised care and strong therapeutic relationships at the point of care. However, they also experienced challenges and emotional impacts during clinical encounters, including feeling dismissed by health professionals in the process of seeking support with care and management for both their CMP and mental health conditions, and described mixed experiences regarding support for their mental health.

Finding 2.3.1: Young people who felt dismissed, invalidated, or unsupported by healthcare professionals experienced negative impacts on their mental health (moderate confidence; 4 reports)

Young people reported how healthcare professionals often lacked compassion and understanding of their life circumstances.[15,65] Healthcare professionals were perceived as dismissive or unwilling to provide guidance or supported self-management, other than around medications.[15,65] This lack of a person-centred and developmentally appropriate approach to care could result in some young people disengaging from care seeking.[15] Many young people described an additional mental health impact through feeling frustrated with healthcare professionals who could not help them or lacked sufficient knowledge in CMP care and their condition.[26] Discussions with healthcare professionals about their pain could bring up uncomfortable emotions, including worry about the pain persisting forever, or a reminder of being different and unable to do what others can. They felt these emotional experiences were not adequately supported by healthcare professionals causing further negative mental health impact.[38]

Finding 2.3.2: Young people with coexisting pain and mental health conditions value support to manage their complex emotions and need to feel comfortable, validated, and understood by health professionals (very low confidence; 2 reports)

Young people described the positive impact of counselling and psychological support, particularly as it related to helping them process complex emotions associated with their pain experiences, and to validate their feeling.[18,35] They also appreciated the opportunity to talk about their emotions and felt validated, secure, and safe as a result.[35] The inclusion of mental health screening questions in the paediatric pain care setting was welcomed, as this screening increased young people's awareness of the emotional impact of their condition and helped them to feel like they were being treated more holistically.[35] However, some experienced discomfort talking with health professionals about their emotions related to pain, or found some mental healthcare professionals did not understand the impact of their pain condition on their mental health, both of which could lead to disengagement from their mental health care.[18,35]

Finding 2.3.3: The importance of strong therapeutic relationships, safe consultation environments, and individualised care for young people living with CMP and mental health conditions (low confidence; 5 reports)

The therapeutic relationship young people have with their healthcare professionals is considered highly important.[38,65,76] Young people value healthcare professionals who understand their circumstances, who they feel they can trust, and who can provide them with individualised care.[38,65] Clear explanations from healthcare professionals about pain (understanding their condition or reasons for their pain), and guidance on how to manage and control their pain helped to reduce the emotional toll and cope better.[38] This extended into healthcare professionals providing young people with much-needed mental health support, and healthcare professionals understanding the two-way interplay between the common experience of coexisting CMP and mental health conditions[65]; something that was described as often overlooked in clinical consultations.[27,35,38] While young people expect clinical consultations to have a strong focus on their pain, they also described the importance of these clinical discussions being undertaken within a comfortable, safe, and age-friendly environment, including topics about them as a whole person, rather than being defined by their pain.[38] For example, young people desire open communication with their healthcare professionals, including discussions around the use of alcohol and drugs, the implications these may have for their condition and management, and what they need to consider for their condition in the long term.[27] For young people who use medication as part of their condition management, they described the importance of strategies to help them remember to take their medication, including pill boxes, calendars, phone alarms, or apps, in addition to individualised treatment plans.[27] Young people also described wanting to understand the side effects of their medication and learn more about their options and choices for the use of medications.[38] Some young people explained they only wanted to be taking prescribed medication where it is important, rather than just quick fixes, that "don't do anything."[65]

3.5. Interpretation of findings

Figure 2 illustrates a model to interpret the findings from this QES. The intersection and interaction of young people's experiences of coexisting CMP and mental health conditions can be interpreted through the lens of a theoretical model of allostatic load.[10,62,64] While allostasis is a normal process through which humans adapt to stressors to maintain physiological homeostasis,[44] this can become dysfunctional under conditions of repeated and prolonged stress, where the term "stress" may capture biological, psychosocial, or physical factors.[45] The cumulative effect of sustained stress in response to interacting CMP and mental health, may result in dysregulation across multiple body systems, including neuroendocrine system, immune system, and brain development.[1,23,64,67]

3.6. Quality appraisal

All reports were assessed using the JBI qualitative tool,[42] (Supplementary File 11, http://links.lww.com/PAIN/C135) with the exception of one report assessed with the JBI tool for cross-sectional studies[18] (Supplementary File 12, http://links.lww.com/PAIN/C135). For the majority of included studies, it was unclear whether there was congruity between the philosophical perspective and the research methodology[5,15,18,22,25,27,30,31,34,35,40,48,52,53,59,60,65,76,80,85]; between the research methodology and the research aims or objectives,[5,18,22,27,30,31,34,35,38,40,71,76] and between the research methodology and the methods used to collect and analyse data.[5,18,22,27,30,31,34,35,38,40,71,76] This was primarily due to a lack of reporting of the philosophical underpinnings and methodological approach of the included studies. Approximately half of the studies located the researchers culturally or theoretically[18,26,30,31,38,49,52,53,58,60,71,80] and addressed the influence of the researcher on the researched, and vice versa.[5,26,31,34,35,38,52,53,59,80] All of the studies adequately presented the participants' voices,[5,15,18,22,25–27,30,31,34,35,38,40,49,52,53,59,60,65,71,76,80,85] all reported institutional ethics approval with the exception of 3 studies,[22,27,34] and all studies had adequate flow from analysis through to interpretations of the data, with the exception of one study.[22]

4. Discussion

Young people living with coexisting CMP and mental health conditions experience a substantial wellbeing burden and challenges to their sense of self. For this QES, the inclusion criterion of coexisting CMP and mental health conditions laid the foundation to explore relationships between these 2 health states, which are commonly experienced by young people as comorbid.[4,54,63] We identified, with moderate confidence, that experiences of CMP and mental health conditions were interrelated. This is consistent with the biopsychosocial model identifying pain and mental health are mediated by shared intrinsic mechanisms,[28] and mental health conditions being described as the "normal psychology of chronic pain."[17] Importantly, the interaction between CMP and mental health conditions can potentially contribute cumulative load to already stressed systems.[11,13,14] Here, mental health symptoms can worsen the experience of pain, and pain can exacerbate or trigger

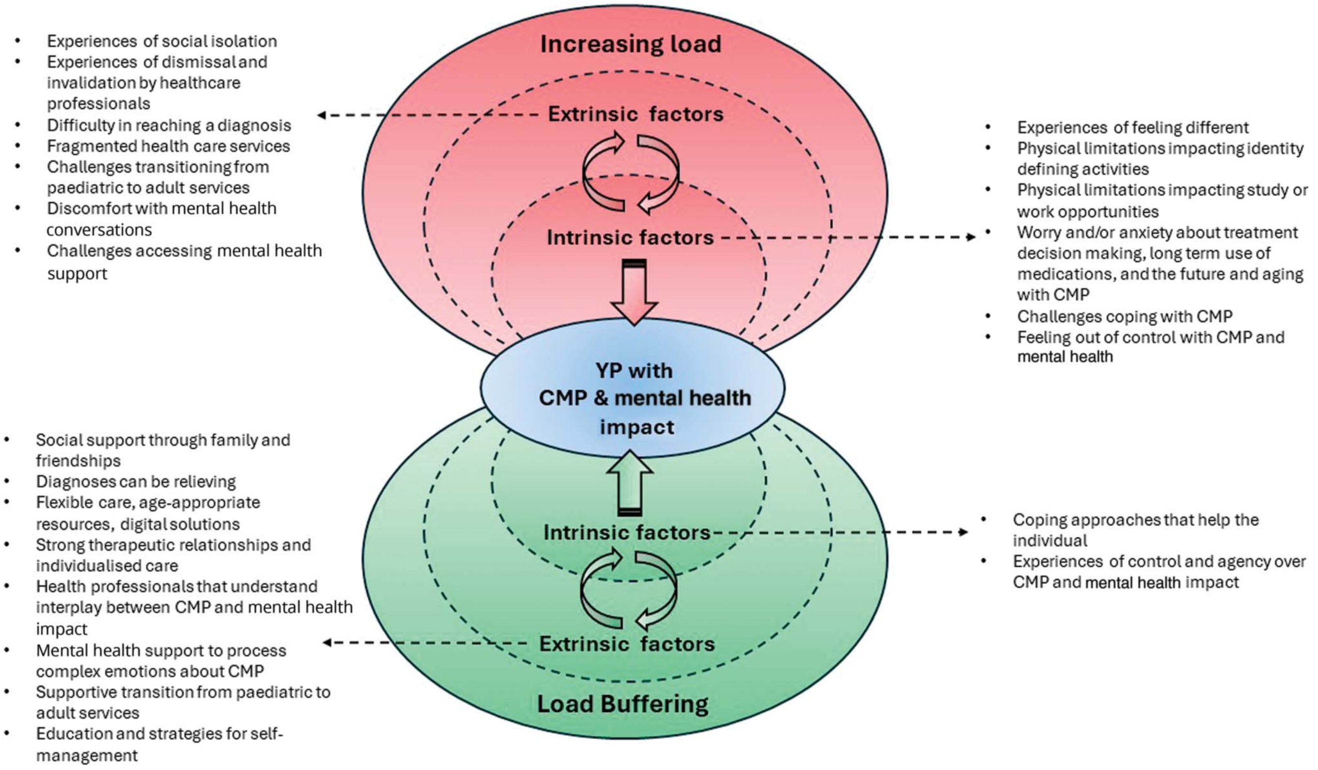

Figure 2. A conceptual model representing an interpretation of the intersection and interaction of young people's experiences of coexisting chronic musculoskeletal pain (CMP) and mental health conditions. In this model, the dynamic interactions of specific intrinsic and extrinsic factors identified from this QES that potentially add load (red shading) or buffer load (green shading) in young people are indicated by arrows and summarized in adjacent dot point lists. In this model, extrinsic factors are considered external to the individual such as medication, health interactions, and social factors, while intrinsic factors are internal and include factors such as physical limitations and emotional states. As denoted by the circular arrows and dotted lines between semicircles, intrinsic and extrinsic factors interact to impact the whole person. The nature of the load experienced by young people can vary, as expressed by the gradient shading within each of the semicircles. The interacting intrinsic and extrinsic factors influencing relative load (ie, cumulative/buffering) may be considered care targets for young people with coexisting CMP and mental health conditions.

mental health symptoms.[28,59] Concurrently, intrinsic (within the individual) and extrinsic (in the individual's external world) factors can further contribute to stress. These findings were largely consistent across primary and secondary CMP conditions, suggesting that for many young people, their experiences were largely agnostic to their diagnosis.

Our findings demonstrate how the interaction between intrinsic and extrinsic factors may either buffer or amplify the experience of CMP and mental health conditions in young people. With moderate to very low confidence, intrinsic factors such as the physical limitations impacting work/study and identity-defining activities, feeling different or stigmatized, worries about the future, challenges coping with symptoms of CMP, and feeling out of control underscore the multifactorial, whole-person experience of CMP and coexisting mental health conditions in young people. Evidence (low to moderate confidence) also suggests the benefit of adaptive approaches to coping with CMP and mental health conditions and young people experiencing control and agency over their CMP and mental health. Extrinsic factors, including social isolation and healthcare experiences, can amplify negative experiences of CMP and mental health. Where intrinsic feelings of worry or being out of control may be mitigated by "helpful" extrinsic healthcare and health service interactions, challenges with the healthcare system at all levels could also exacerbate negative experiences (moderate to very low confidence). Evidence (very low to moderate confidence) further indicates the importance of extrinsic factors that may buffer the load experienced by young people, including social support, and healthcare that is integrated, individualized, built on trusted therapeutic relationships, and which considers the intersection between CMP and mental health.

The perceived cumulative burden from intrinsic and extrinsic factors in young people with coexisting CMP and mental health conditions is interpreted through a model of allostatic load[10,62,64] and depicted in **Figure 2**. Here, the compounding role of stressors, such as those identified in this QES, may have particularly profound effects during stress-sensitive developmental stages.[21,36,61,72,74,77] Importantly, young people experience significant biologic changes to hypothalamic–pituitary–adrenal (HPA) axis activity.[20,24,36,70] During this period, the presence of multiple or sustained stressors can result in alterations in nociceptive processing, demonstrated by heightened pain sensitivity (possibly suggesting blunted diffuse noxious inhibitory controls/amplified nociception),[78] in addition to negative impacts on young people's mental health.[6,7,56] Changes to HPA axis plasticity during development may contribute to the increased risk of experiencing mental disorders into adulthood. For example, sustained exposures during adolescence (such as those identified in this QES) may increase the risk of posttraumatic stress disorder, anxiety, and depression later in life.[43,54] Collectively, these interacting intrinsic and extrinsic factors influencing relative load (ie, cumulative/buffering) may be considered specific care targets for young people with coexisting CMP and mental health conditions.

4.1. Clinical care implications

Our findings highlight evidence for the cumulative load of personal, social, and healthcare experiences having a potentially profound and enduring impact on young lives, highlighting the importance of timely, integrated, and whole-person care. Transdiagnostic, integrated personalized care models that address shared underlying mechanisms of pain and mental health,[41] and respond to the whole person, could improve young people's lived and care experiences. For example, our findings clearly highlight that these young people prioritize mental health care as part of their CMP care. Here, care models that integrate age-appropriate and personalized care plans, reduce unnecessary and potentially harmful care (including unnecessary clinical encounters), and focus on building young people's confidence and resilience are key targets to improve young people's experiences and health outcomes.

In this context, our QES findings highlight multiple strategies that young people reported for how care may be improved to better align with a whole-person, integrated, transdiagnostic care model. Young people value healthcare professionals who view them as a whole person (not defined by their pain) and personalize care to help improve their overall wellbeing, including focused consideration of their mental health. Key clinical skills include empathic communication, time spent building therapeutic alliance and trust, and creating space to listen to, and validate, young people's experiences. These skills are not explicitly outlined in clinical practice guidelines,[9,29] and, to our knowledge, specific age-appropriate clinical training and guidelines for this target age/condition do not exist. Yet, our findings suggest these skills may have direct therapeutic effects and moderate the stress-load experienced by young people during clinical encounters.[37,66] Young people detailed the importance of flexible health services, including streamlined diagnostic processes, and a desire for combining interdisciplinary appointments and offering flexibility to manage the demands of education and work. Here, models of interdisciplinary collaborative-care could offer holistic and better integrated care experiences. Such service models could reduce the burden on young people of multiple fragmented appointments.[19] Diagnosing conditions and monitoring lived experience impacts, framed through a contemporary understanding of CMP and mental health, may improve the quality of person-centered care by better enabling delivery of personalized services.[16] Virtual care models (ie, digitally enabled) were endorsed by young people. Digitally enabled models may augment clinical co-care offering time-critical scalable support and safety-netting between appointments or during extensive wait periods.[68] Last, young people were explicit in the need for a supportive, graded transition from paediatric to adult services, to prevent them from falling through care "gaps."[65] While current care guidelines across CMP conditions advocate for consideration of psychological contributors,[9,29] critical implementation guidance on integrated care specific to this transitional age group is lacking.[47,49,55]

4.2. Strengths and limitations

This is the first QES exploring the lived and care experiences of young people (16-24 years) with CMP and mental health conditions. The comprehensive search across databases from inception ensured sensitivity to capture the breadth of domains relevant to lived and care experiences across all CMP conditions for this age group. The available data were limited to research in high-income nations and one upper-middle-income nation,[58] with reports including a range of CMP conditions (diagnoses) and ages, enhancing the relevance of these findings across settings and populations. We acknowledge a substantial knowledge gap related to the experiences of young people outside high-income countries and potentially young people experiencing significant intersectoral disadvantage within high-income countries, as well as young people from diverse cultural backgrounds. Additional strengths of the QES included dual independent screening of citations and reference lists, data extraction, quality appraisal, assessment of confidence aligned with the GRADE-CERQual approach,[39] and including a young person with lived experience on the review team (B.T.) to assist with interpretation and framing of the findings. Recognizing that only one primary study had been published within the period of review that explicitly aligned with our research question,[15] we systematically interrogated other primary studies to include, where relevant, subsets of data that could contribute to the synthesis, increasing our confidence that all available data to May 2024 were included. Reporting quality in primary studies was often poor, particularly for earlier published reports, with only 6 reports[27,31,38,58,65,80] citing the use of a standard reporting checklist. The lack of detailed reporting limited our data extraction and ability to summarize the demographic and clinical characteristics for one report.[18] This issue also contributed to quality appraisals that identified potential biases and limitations in some primary studies, impacting GRADE-CERQual judgements on methodological limitations. Finally, the included sample also largely reflected young people with autoimmune conditions such as JIA and SLE (71%), limiting transferability to young people with primary CMP conditions.[51]

5. Conclusions and future directions

Prioritising age-appropriate and timely care for young people with coexisting CMP and mental health conditions as they transition from adolescence to adulthood is of high importance given the potential for enduring burden on young lives. Our findings highlight areas for developing novel integrated care models that better cater to young people's individual CPM and mental health needs, building confidence and resilience, and moderating cumulative stress-load. While current care guidelines point towards the importance of integrated care for CMP and mental health,[9,29] significant gaps remain for the implementation of such care in this developmentally sensitive age group and across settings. Evidence for what care works for this young people population, including what "dose," what components of care, for whom, when, and in which settings remains limited, highlighting an area where future research is needed. This information will help guide the development of novel care models to support young people living with CMP and mental health conditions.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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