

Report Supplementary Material File 4

Findings of included studies

Authors' findings (first or second order constructs) from included studies and our 2nd order constructs (interpretations of any descriptive findings)

Pain Condition Grouping	Authors' findings (first-order constructs, e.g. descriptive themes, or second-order constructs, e.g. concepts) from included primary studies	Review authors' second-order constructs from our initial interpretation of the study (created if author findings were descriptive)
Sickle Cell Disease	Atkin ¹ <ul style="list-style-type: none"> • Coping with a haemoglobinopathy <ul style="list-style-type: none"> - Family relationships and coping • Service provision, coping and racism <ul style="list-style-type: none"> - Competence of health professionals - Information • The vulnerability of coping strategies 	<ul style="list-style-type: none"> • Balance • Embrace medical model • Engulfment • Mastery • Positive framing & normalisation • Racism • Religion
	Atkin ² <ul style="list-style-type: none"> • Coping with a chronic Illness <ul style="list-style-type: none"> - Coping with uncertainty - Religion and coping - the importance of medical information - Social and emotional factors • Coping with the response of others 	<ul style="list-style-type: none"> • Maintaining sense of normalcy • Ambivalent Relationship with parents • Disabling attitudes and discrimination • Dynamic nature of coping • Guilt and coping • Healthcare professionals lack of knowledge and ignorance • Maintaining a positive framing • Medical Model& coping • Peer relationships • relationships with healthcare professionals • Religion and coping • Social Support Why me? Sense of difference
	Atoui ³ <ul style="list-style-type: none"> • Pain** • Divine intervention*** • Family as a source of support and a source of guilt • Psychosocial and physical limitations • School issues 	<ul style="list-style-type: none"> • Defined and limited by pain • Downplaying pain and acceptance [Nb these 2 concepts were analysed in addition to the descriptive themes on the left]
	Dyson ⁴ <ul style="list-style-type: none"> • Capital gained capital lost 	<ul style="list-style-type: none"> • Capital - Being excluded from school and peers*

	<ul style="list-style-type: none"> • Habitus and fragile dispositions • The field of the school- habitual ‘dys-positions’ 	<ul style="list-style-type: none"> • Capital - The impact of social class • Field of clinic - School routines undermines self-care • Field of school – Pain and condition undermines learning • Field of School - School lacks support structure • Habitus - Lack of understanding • Habitus - Pressure to account for themselves or to explain condition* • Habitus - The dilemma of disclosure • Habitus - Transforming fragile dispositions through school policies
	<p>Renedo⁵</p> <ul style="list-style-type: none"> • Barriers to receiving good, personalised and responsive care not being heard <ul style="list-style-type: none"> - Being denied timely and adequate pain relief - Body management and basic care needs ignored • Feeling out of place unwelcoming adult wards • Trying hard to stay out of hospital 	Not applicable (authors’ findings were conceptual not descriptive)
	<p>Njifon⁶</p> <ul style="list-style-type: none"> • The adults' behaviour (Comportement des adultes) • The way in which the illness affects the family unit (Du «on» à l’impact de la maladie sur le groupe familial)* • Guilt (La Culpabilité) <ul style="list-style-type: none"> - Aggression directed at the ill child (Agressivité dirigée contre le malade) - Painful feeling of powerlessness (Dououreux sentiment d’impuissance) - The children's guilt (La culpabilité des enfants) • The meaning of SCD (La drépanocytose, son sens) • The question of death (La question de la mort) <ul style="list-style-type: none"> - Death of the ill child and survival of the illness (Mort Du Malade & Survie De La Maladie)* - A fear that never ends (Une peur qui ne cesse jamais) • Loneliness & adults lack of interest (La solitude et le manque d’intérêt des adultes)* • Is the sick child a brother? (Le malade est-il un frère?)* 	Not applicable
Unspecified type of chronic pain	<p>Nutkiewicz⁷</p> <ul style="list-style-type: none"> • Separate orientations/ separate vocabularies • What oral testimonies teach us about the world of children in pain 	<ul style="list-style-type: none"> • What makes a good doctor • The social and private world of children in pain • Search for a diagnosis is frustrating • Patients seek more than pain relief • Children are frustrated with treatment • Children and their doctors have two separate orientations

	<p>Kanstrup⁸</p> <ul style="list-style-type: none"> • ‘Warning system’ <ul style="list-style-type: none"> - Buying into a psychological approach - Reframing the Experience of pain • Change and Challenges <ul style="list-style-type: none"> - Values - doing what matters to you - ‘Getting the idea’ -the need for adaptation • ‘A common Language’ <ul style="list-style-type: none"> - Thinking outside the bubble • A new dialogue 	Not applicable
Neurological Conditions	<p>Carter⁹</p> <ul style="list-style-type: none"> • Making decisions: managing pain and dealing with professionals • Dealing with Uncertainty • Expression of pain • Learning to live with pain 	<ul style="list-style-type: none"> • Dealing with professionals • Making decisions managing pain
	<p>Hunt¹⁰</p> <ul style="list-style-type: none"> • Identifying pain <ul style="list-style-type: none"> ○ A process of elimination - hypothesis testing ○ Comparing with normal - knowing the child ○ Inferring pain ○ Intuition ○ Paying attention to parents and child • Management of pain <ul style="list-style-type: none"> ○ Clinical and ethical decision making • Types of pain 	Not applicable
	<p>Castle¹¹</p> <ul style="list-style-type: none"> • Being in pain • Doing anything to get rid of the pain • Enlisting help • Fighting the pain • Looking ahead • Making sense of the pain • The experience of chronic pain 	Not applicable
	<p>Carter¹²</p> <ul style="list-style-type: none"> • Developing a sense of knowing <ul style="list-style-type: none"> ○ Learning to be a convincing advocate ○ Learning to endure and finding a balance ○ Learning to know without a rule book or guide 	Not applicable

	<p>McKinnon¹³</p> <ul style="list-style-type: none"> • The continual challenge of problem solving pain and dyskinesia • The pursuit of a solution • Unfulfilled preferences within pain management • All-encompassing effects on families • The ongoing impacts of pain and dyskinesia with age 	Not applicable
Musculoskeletal chronic pain	<p>Khanom¹⁴</p> <ul style="list-style-type: none"> • Daily life with pain • Pre-flare period • Pain flare period • Post-flare period 	<ul style="list-style-type: none"> • Pain affects young people's relationship with family members • Persistent/constant background pain becomes 'normal' to children and young people • Uncertainty & anxiety - Fluctuating nature of (complex regional pain syndrome/juvenile idiopathic arthritis) pain with pain 'flares'- difficult to manage pain & leads to uncertainty re consequences on children and young people's future, anxiety & psychological impact of the pain
	<p>Forgeron¹⁵</p> <ul style="list-style-type: none"> • Dealing with the pain • Healthy is being normal • Management strategies • Relating to friends • Relating to peers & society interferes with being normal • Struggling to be normal • Transitioning - not yet • Trying to be normal at school 	<ul style="list-style-type: none"> • The challenges of transitioning to adult clinic- not ready for adult care, still dependent on parental involvement • Strategies to help young people to do well in school • Frustration young people trying to succeed in school despite missed schooling • [Young people] support from another peers with chronic pain • Use of analgesics • Young people see restrictions caused by pain as unhealthy (pain is not 'normal' and healthy) • Trade-off - children and young people trade off fun activity (e.g. they 'pack it in' when feel well) for the necessary consequence of increased pain • Stigma- Feel stigmatised by acquaintances/strangers reactions to and treatment of them • Paradox of children and young people viewing themselves as different/abnormal but not wanting to be seen by others as different
	<p>Ahlqwist¹⁶</p> <ul style="list-style-type: none"> • Compliance with physiotherapy • Gaining energy from pain free moments • Mobilizing their own resources • Coaching from the physiotherapist • Seeking for information 	<ul style="list-style-type: none"> • Children and young people developing awareness of their bodies and pain [& being aware of inherent capabilities] • [Children and young people] Seeking information • Children and young people's trust in physiotherapist and hope of cure/pain relief • Adherence/compliance [children and young people] • Positive aspects of treatment/physio programme (control) [children and young people]

		<ul style="list-style-type: none"> • Children and young people empowerment through physio programme/empowerment of children and young people through successful outcomes from physio • Contextual understanding of low back pain from physio (such info was not found through children and young people searching internet sources) helps with finding a solution to pain
Abdominal Pain	Brodwall ¹⁷ <ul style="list-style-type: none"> • desire for a specific diagnosis and discussion with a professional • How the pain rules the family • Interpreting and handling the child's pain 	Not applicable
	Smart ¹⁸ <ul style="list-style-type: none"> • Beliefs about doctors • Beliefs about mothers • Beliefs about the pain • Interactions with doctors 	<ul style="list-style-type: none"> • Child health is a mother's responsibility
Complex Regional Pain Syndrome	Gaughan ¹⁹ <ul style="list-style-type: none"> • Suffering and disempowerment <ul style="list-style-type: none"> ○ Parent Distress <ul style="list-style-type: none"> ▪ Disabled Parenting ▪ Schism in Parenting ▪ Searching ▪ Lack of control ▪ Family - Community ▪ Fear • Empowerment 	<ul style="list-style-type: none"> • Readmission
	Jones ²⁰ <ul style="list-style-type: none"> • Adjusting to Loss • Centrality of Loss 	Not applicable
Dysmenorrhea	Wong ²¹ <ul style="list-style-type: none"> • Lifestyle changes <ul style="list-style-type: none"> ○ Careful selection of diet ○ Reduced physical activity • Symptom management <ul style="list-style-type: none"> ○ Heat therapy ○ Self-medication • Communicating dysmenorrhea with others <ul style="list-style-type: none"> ○ Family ○ Friends • Seeking medical advice <ul style="list-style-type: none"> ○ Western medical practitioners ○ Chinese medicine practitioners 	<ul style="list-style-type: none"> • Self-care Strategies • Dysmenorrhea as 'normal pain' that has to be endured • Embarrassment associated with menstruation [impairs communication about period pain] • Mothers assume responsibility for their child's pain management • Girls suffer unnecessary pain

Epidermolysis Bullosa	Williams ²² <ul style="list-style-type: none"> • Talking about those with worse epidermolysis bullosa • The importance of belonging • Physical activity and identity • Self as 'wrong' • Self As 'burden' • Self As different • Self As weak • Special Treatment • Expression of feelings as unacceptable • Helplessness • Lack of understanding regarding epidermolysis bullosa Negative treatment from others - Visibility & Contagion • Control Over Physical activity • Coping with pain • Defining self in terms of physical activity 	<ul style="list-style-type: none"> • Young people's beliefs on their own experiences [causes feelings of guilt] • Support from peers with epidermolysis bullosa [young people] • Self-identity [young people] • Stigma [young people] • Describing pain is difficult for young people • Young people's dependence on mother • Young people gaining a sense of choice by prioritising physical activity • Young people dealing with feelings about/managing condition
Headache	Helvig ²³ <ul style="list-style-type: none"> • Disengage and isolate self • Mind overload • Unsettling manifestations – Physical • Unsettling manifestations – Psychological • Maintaining control • Press on and endure the burden 	<ul style="list-style-type: none"> • Uncontrolled pain • Unknown cause of pain
Juvenile idiopathic arthritis	Britton ²⁴ <ul style="list-style-type: none"> • Siblings perspective <ul style="list-style-type: none"> ○ Play, leisure & troubled sibling relationships • Recognition of grandparents contributions • Perspectives of children with arthritis <ul style="list-style-type: none"> ○ Feeling different ○ Children and pain • Mothers' experiences <ul style="list-style-type: none"> ○ Cycles of parental grieving (chronic sorrow) • Fathers' experiences 	<ul style="list-style-type: none"> • Wider family support • Shared sense of parent child identity with regard to juvenile idiopathic arthritis • Parent's life greatly changed • Parental helplessness and powerlessness • Parental healthcare professionals communication • Feeling different • Life greatly changed • Enhanced sibling protectiveness and compassion • Cyclical mastery of skills and self-perception • Cycles of parental grieving (chronic sorrow) • Normal to be in pain • Becoming a carer not just a parent • Experiences of health services
	Britton ²⁵ <ul style="list-style-type: none"> • The families' experience of splinting • Families' experiences of exercise programmes 	<ul style="list-style-type: none"> • Psychosocial impact of disease and management is key <ul style="list-style-type: none"> ○ Psychosocial impact neglected by healthcare professionals ○ Ill child focus in home

	<ul style="list-style-type: none"> ○ Time taken to undertake exercise routine ○ Stages in families deciding their own level of adherence ○ Parents' feelings about supervising the exercise routine ○ Pain and boredom ○ Maternal 'sense of mastery' ○ Maternal reticence to seek advice ○ Learning that exercises were important ○ Conflicting advice from professionals ○ Conflict between parents ● Unpredictable times of adversity ● Predictable times of distress ● Model of families' experience of living with a child with arthritis 	<ul style="list-style-type: none"> ○ Conflict over physio ● Parents Knowledge of regimen affects adherence and efficacy ● Pain and boredom from physiotherapy ● Inconsistent healthcare professionals advice undermines trust ● Family factors affecting physiotherapy adherence ● Barriers to accessing services <ul style="list-style-type: none"> ○ Consequences of difficulties accessing services
	<p>Rossato²⁶</p> <ul style="list-style-type: none"> ● Care delivery for the child to grow up <ul style="list-style-type: none"> ○ Wanting to see the child free from pain <ul style="list-style-type: none"> - Having to live with uncertainties - Living in function of the child - Overcoming barriers - Wanting to get out of this nightmare ○ Wanting to see the child lead a normal life <ul style="list-style-type: none"> - Leading the child's life normally - Preparing the child to live with the disease situation - Waiting for a miracle ● Wanting a good future 	<ul style="list-style-type: none"> ● Managing uncertainty ● Want miracle, end nightmare ● Balance ● Complexity of a diagnosis ● Establishing normalcy over time
	<p>Guell²⁷</p> <ul style="list-style-type: none"> ● Normal Childhoods <ul style="list-style-type: none"> ○ Feeling Healthy ○ Hiding Illness ○ Normalizing Abnormality ● In the Face of Uncertainty <ul style="list-style-type: none"> ○ Disciplining the Body ○ Facing Diagnosis ○ Learning the Language ○ Taking Control ● Sheltered Bodies & Mature Minds <ul style="list-style-type: none"> ○ Cosseting Childhoods <p>Taking Responsibility and Making Decisions</p>	
	<p>Waite-Jones²⁸</p> <ul style="list-style-type: none"> ● Social contagion ● Social comparison ● Social and emotional adjustment 	

	<ul style="list-style-type: none"> • Emotional contagion • Amplified ambivalence 	
	<p>Cartwright²⁹</p> <ul style="list-style-type: none"> • Striving to be a normal teenager • Resilience though taking control <ul style="list-style-type: none"> ○ Taking charge and overcoming limitations ○ Social support as an enabler ○ Minimization and distraction ○ Disclosure or concealment • Burden of juvenile idiopathic arthritis <ul style="list-style-type: none"> ○ The future and managing uncertainty ○ Physical vulnerability and isolation • Acceptance and self-growth 	
	<p>Brandelli³⁰</p> <ul style="list-style-type: none"> • Shifting roles • Altered relationships • Emotional well-being • Internal conflict 	
	<p>McDonagh³¹</p> <ul style="list-style-type: none"> • Struggle for help <ul style="list-style-type: none"> ○ Divergence in Care ○ A Fight for Everything ○ Need for Support • Mothers know best <ul style="list-style-type: none"> ○ Parent and Child Communication ○ Social Support between Mothers • Daily impacts <ul style="list-style-type: none"> ○ Living a Life for Two People ○ Not a Regular Family 	
Mixed types of chronic pain	<p>Carter³²</p> <ul style="list-style-type: none"> • No one's pain's the same, it's always there • Getting on with it • It depends... some are OK 	
	<p>Carter³³</p> <ul style="list-style-type: none"> • The quest for a diagnosis and referral fatigue • Professional Judgement and disbelief • Professionals who believed the family • Communication or Ventriloquism 	
	<p>Maciver³⁴</p> <ul style="list-style-type: none"> • Complex parenting • Development of adaptative responses to child's distress 	<ul style="list-style-type: none"> • Parental Efficacy • Stepping back • Loss of normal parenting role

		<ul style="list-style-type: none"> • Fearful responses from parents • Being on call • Disrupted development
	<p>Maciver³⁵</p> <ul style="list-style-type: none"> • The in-patient pain management programme experience • Practical and emotional support • Relationships with professionals • Misaligned expectations • Pain conveying difficult messages to parents • Disenchantment 	
	<p>Maciver³⁶</p> <ul style="list-style-type: none"> • The prediagnosis phase - Diagnosis • Prediagnosis - Parental responses searching for information • The prediagnosis phase • Prediagnosis Phase - Expectations • Prediagnosis - Medical disbelief • Treatment - Wheelchairs and walking misaligned goals • Treatment - The role of the psychologist • Treatment - Tertiary referral service pain clinic • Treatment - Tertiary referral serviced inpatient pain management • Treatment - Pain conveying difficult messages to parents • Treatment - Continuing disbelief • Treatment - Expectations • Treatment - Being in hospital • Parenting - Striking a happy balance • Parenting - Uncertainty • Parenting - Sadness • Parenting - Sleep deprivation • Parenting - Pacing and balance • Parenting - Not being able to plan for the future • Parenting - Not being normal • Parenting - nonnormative, failed and disrupted parenting • Parenting - Normal Childhoods and normal families • Parenting - Marital tension • Parenting - Losing the opportunity to be spontaneous • Parenting - Loss of work • Parenting - Impact on self emotional and practical consequences • Parenting - Living a restricted Life • Parenting - Fear of the future • Parenting - Helplessness 	

	<ul style="list-style-type: none"> • Parenting - Engulfment • Parenting - Encouraging communication • Parenting - Encouraging discouraging participation in activities • Parenting - Dealing with the emotional impact on the child • Parenting - Developing adaptative responses to the child's distress • Parenting - Being on call • Parenting - Complex parenting • Parenting - Anger, depression and behaviour problems • Parental - Practical Consequences • Parental - Emotional consequences • Healthcare struggling for support 	
	<p>Dell'Api³⁷</p> <ul style="list-style-type: none"> • Difficulties in living a normal life • Wiping their hands clean • The search for understanding • They don't believe me • Seeing is believing • Sometimes they are helpful, sometimes they are not • Pain is something that can't be cured • Perceptions of chronic pain influenced by health care professional interactions • If they can't see it, it is not there • Impact of previous experiences on current encounters with health care professionals • I must be dying • Fears for the future • Guarded alliance living with scepticism 	
	<p>Jordan³⁸</p> <ul style="list-style-type: none"> • What's next • Not going back • In limbo • Diagnosis as proof of pain • Fight for resources 	
	<p>Borgi³⁹</p> <ul style="list-style-type: none"> • Seeking a life that is closer to normality • Using various alternatives for managing pain • Living with a damaged self-image 	
	<p>Jordan⁴⁰</p> <ul style="list-style-type: none"> • Helplessness 	

	<ul style="list-style-type: none"> • Re-evaluation • Containment 	
	<p>Suder⁴¹</p> <ul style="list-style-type: none"> • Uphill climb to regain life • Uncertainty of disease • Unknown future • Push through the pain • Pain becoming the main occupation • Pain identity • Occupational loss • Invisible disease • Loss of independence • Changes in self • Fabrication of symptoms 	
	<p>Jordan⁴²</p> <ul style="list-style-type: none"> • An externally imposed lens on identity • Paradoxes of developmental progress 	
	<p>Neville⁴³</p> <ul style="list-style-type: none"> • Mistrust in the medical system • Haunted by something missing • The function of a Diagnosis 	
	<p>Baert⁴⁴</p> <ul style="list-style-type: none"> • You're making it up • Describing pain • Not everybody gets a healthy child • The problem is problem with the mother • At least it's not cancer 	
	<p>Jones⁴⁵</p> <ul style="list-style-type: none"> • Tug of war: push and pull <ul style="list-style-type: none"> ○ The shifting sands of peer relationships ○ Restricted choices 	

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