JAFA
Juvenile Arthritis Foundation Australia

THE IMPACT STUDY

Investigating the Mental, Physical, Social And Financial CosTs of Juvenile Idiopathic Arthritis and Related Childhood Rheumatic Diseases

November 2023

ACKNOWLEDGEMENTS

The funders

The Juvenile Arthritis Foundation Australia (JAFA) sincerely thanks Adrian and Charlotte MacKenzie and Five V Capital for their generous donation which enabled JAFA to commission this important study documenting the magnitude of the hidden impacts of juvenile idiopathic arthritis and childhood rheumatic diseases on affected children and young people and their families.

The researchers

JAFA is grateful to the research team for their expert knowledge, skills and dedication to undertaking this research and preparing the report:

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The advisory committee

JAFA thanks the consumer representatives, Paul Cassar and Nicole Myers and paediatric rheumatologist, Dr Georgina Tiller for their valuable advice on the survey questions.

The participants

JAFA especially is grateful for the contribution of the parents who piloted the survey questionnaire and the families and young people who made the IMPACT Study possible by committing their time and emotional energy to completing the survey.

Suggested reference

Bond DM, Von Huben A, Lain S, Colagiuri R, Colagiuri S, Nassar N. *The IMPACT Study: Investigating the Mental, Physical, Social And Financial CosTs (IMPACT) of Juvenile Idiopathic Arthritis and Related Childhood Rheumatic Diseases*. Juvenile Arthritis Foundation Australia, Sydney. November, 2023

PURPOSE OF THE IMPACT STUDY

The IMPACT Study represents a major step in JAFA's agenda to measure the extent of the burden of juvenile idiopathic arthritis and childhood rheumatic diseases on affected individuals, their families, and society more broadly. JAFA's overarching purpose in commissioning this study is to raise awareness of these painful and limiting diseases and provide an evidence-based case for equitable investment in services and research to improve access to diagnosis and care and optimise outcomes.

The IMPACT study contributes to this by:

- Documenting aspects of the mental, physical, social and financial burden and the unmet needs of individuals and families living with these diseases
- Identifying priority areas where the experience and reality of risk, disadvantage and disability can be reduced and outcomes improved
- Establishing a baseline for designing and evaluating future interventions.

FOREWORD

While we still have much to learn about juvenile idiopathic arthritis and related childhood rheumatic diseases, I am delighted to introduce this comprehensive report which represents an important milestone in gathering much needed evidence to guide the national effort to reduce the burden of these diseases on affected children and young people and their families.

The IMPACT Study speaks to the recommendations of the 2022 *Interim Report on the Parliamentary Inquiry into Childhood Rheumatic Diseases* and is the first comprehensive Australian study to systematically investigate and describe the previously hidden impacts of childhood rheumatic diseases. As the IMPACT Report illustrates, these diseases carry a significant burden of pain, physical limitations, mental and emotional distress, social isolation, poor quality of life, lost educational opportunity, and financial costs. And, in susceptible families, can create or severely exacerbate long lasting socio-economic disadvantage.

I am proud of the contribution the IMPACT Study makes to developing the evidence base about these diseases and their personal and public costs. The expanded knowledge and understanding these findings add to current awareness and evidence of these diseases will add considerable value in assessing their overall burden and informing decision making and further research.

The Juvenile Arthritis Foundation Australia is grateful to the donors and research team for making this possible.

I commend this Report to you,

Andrew Harrison
Chair, Juvenile Arthritis Foundation Australia
November 27, 2023

CONTENTS

ACRONYMS

ABS	Australian Bureau of Statistics
AUD	Australian dollars
CHU9D	Child's Health Utility
CRD	Childhood rheumatic disease
DMARD	Disease-modifying antirheumatic drugs
bDMARD	Biological disease-modifying antirheumatic drugs
csDMARD	Conventional synthetic disease-modifying antirheumatic drugs
tsDMARD	Targeted synthetic disease-modifying antirheumatic drugs
GI	Gastrointestinal
GP	General Practitioner
IVIG	Intravenous Immunoglobulin
JIA	Juvenile Idiopathic Arthritis
OT	Occupational Therapist
QoL	Quality of Life
MRI	Magnetic resonance imaging
NSAID	Non-steroidal anti-inflammatory drug
PedsQL	Pediatric Quality of Life
SD	Standard Deviation

RESULTS AT A GLANCE

Juvenile Idiopathic Arthritis

Diagnosis

- The average age of symptom onset was 5 years.
- The average time to diagnosis was 11 months.

Treatment and Care

Medications

- 97% took a medication for JIA in the past year
- 68% had taken 3 or more medications
- 74% had taken a csDMARD, most commonly Methotrexate
- 53% had taken a bDMARD, most commonly Adalimumab
- 73% had taken a NSAID
- Corticosteroids - oral (38%), injections (45%),
- Overall, 72% experienced side effects – most commonly with Methotrexate (70% of users)
- GI symptoms and malaise were the most common side effects of most medications.

Health Professional Visits

In the past year participants:

- Visited an average of 25 health professionals: 5 GP, 8 clinical specialist, 11 allied health
- Saw an average of 5.6 different professionals
- Additionally, 30% were unable to access a service due to cost eg physiotherapist, psychologist, OT, hydrotherapy.

Medical Tests and Hospitalisations

In the past year:

- 97% had one or more tests eg blood tests (95%) and eye examinations (78%)
- 56% had at least one hospitalisations of which 80% were day-stays
- Average of 2.0 hospitalisations per year
- The commonest reasons for 1 or more nights in hospital were: pain/inflammation (41%) and infections (38%).

Impact

Physical, Emotional and Social

- 50% reported moderate to severe pain over the past week. Only 15% reported no pain.
- 30% required orthotics/splints/braces
- 32% had an eye condition
- 53% a mental health condition
- Students missed an average of 2.6 (12%) school days per month
- Emotional health was impacted in 75% of children and 59% of families participation in leisure activities, (68% of children, 42% of families) and sport (77% of children).

Quality of Life (QoL)

- Children with JIA had a considerably lower QoL score (0.53) than the Australian norm for adolescents aged 11-17 (0.78) and for children with other chronic conditions.

Financial Cost Estimated (AUD 2022)

- Annual cost per participant was AUD 28,688
  - government health care costs: $24,396
  - participant out of pocket costs: $ 4,292

Priorities for future research

The three priority areas were:

- long-term health impact,
- medication side-effects and effectiveness
- physical impacts (pain, fatigue, flares).

Childhood Rheumatic Diseases

(Key findings)

Diagnosis

- Average time to diagnose was 14 months
- 27% were diagnosed after 1 year

Treatment and Care

- 71% were taking csDMARDS, 43% bDMARDS, 49% NSAIDs, and 57% oral corticosteroids.
- Average of 4.0 hospitalisations per year.

School

- Students missed an average of 3.1 (15%) school days per month

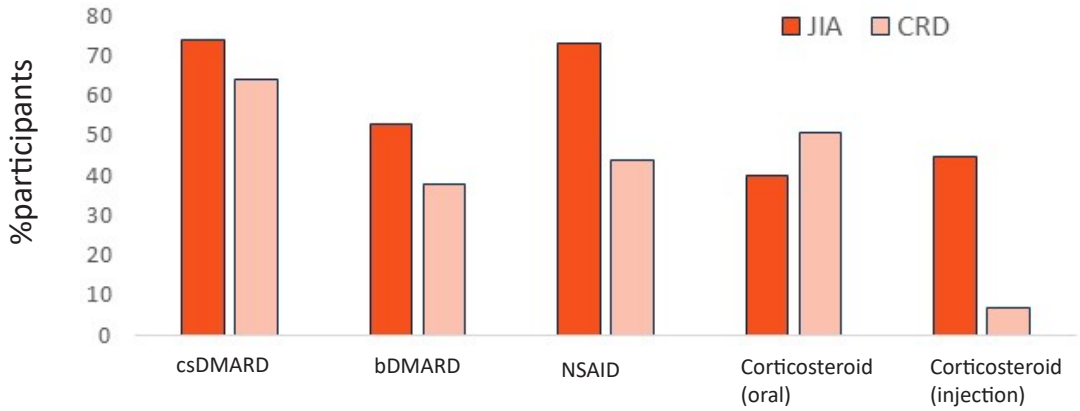
Financial Cost Estimated (AUD 2022)

- Annual cost per participant was AUD 35,368
  - government health care costs: $31,189
  - participant out of pocket costs: $ 4,179

RESULTS AT A GLANCE

DIAGNOSIS	JIA	CRD
Average age of symptom onset	5 years	6 years
Average time to diagnosis	11 months	14 months

TAKING MEDICATIONS	97%	98%
Types of medications		



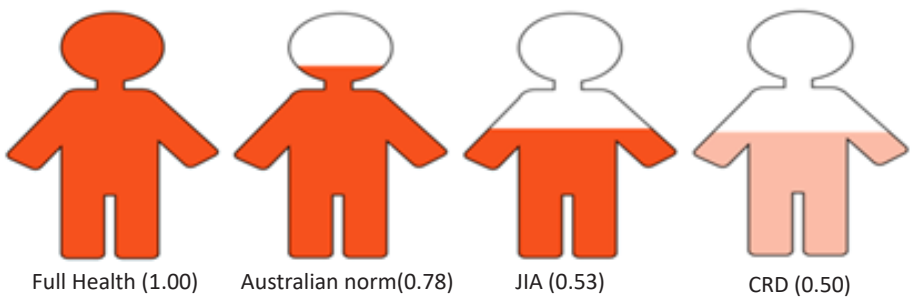
Side Effects	72%	57%

HEALTH PROFESSIONAL VISITS	JIA	CRD
Average visits per year	25	26
Number of different health professionals	5.6	6.4

HOSPITALISATIONS	JIA	CRD
Hospitalised per year	56%	57%
Average number of hospitalisation per year	2.0	4.0

FINANCIAL COST (AUD 2022)	JIA	CRD
Total cost per person per year	AUD 28,688	AUD 35,368
Government health care costs	AUD 24,396	AUD 31,189
Out of pocket costs	AUD 4,292	AUD 4, 179

QUALITY OF LIFE



INTRODUCTION

About Juvenile Idiopathic Arthritis and Childhood Rheumatic Diseases

Juvenile idiopathic arthritis (JIA) and related childhood rheumatic diseases (CRDs) are a group of painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. JIA accounts for approximately 80% of all CRDs with the remaining 20% made up of less common conditions such as systemic lupus erythematosus, chronic relapsing multifocal osteomyelitis and juvenile dermatomyositis.

JIA affects an estimated 6,000 to 10,000 Australian children aged 0-16 years, and 18-30,000 Australians aged 0-24 years, equivalent to diabetes in the same age group.[1] Awareness of JIA is so low among health professionals that children can present with permanent joint damage and loss of vision at the time of diagnosis.[2,3] 80% of children experience daily pain and suffer a high burden of permanent disability, time off school and lost educational opportunity, social and physical marginalisation, and mental ill health including anxiety, depression[,4] and suicidal ideation.[5] 20% of children with oligoarticular JIA have uveitis, an inflammatory eye disease that causes visual impairment and blindness if not detected early and treated.

In 50% of affected children, arthritis continues into adulthood accounting for tens of thousands of adults with severe disability. Adults with arthritis beginning in childhood suffer increased physical and mental health impacts compared with those whose arthritis started in adulthood.[4]

Previous research put the **average time from the onset of symptoms to a diagnosis of JIA in Australia at 10 months**[6], with children seeing multiple clinicians and often undergoing unnecessary, expensive and painful investigations. This critical delay in commencing effective therapies narrows the window of opportunity for early remission and positive long term outcomes, and causes distress to families and avoidable pain and suffering for the child or young person.

The treatment of JIA and CRDs is highly complex and involves the use of powerful immunomodulating medications, steroids and anti-inflammatories, all of which can have serious short and long-term side effects. Many children also require frequent joint aspiration and/or corticosteroid injections under general anaesthetic. Many suffer unpredictable acute 'flares' which may require hospitalisation. Ongoing clinical monitoring and access to specialist multi-disciplinary teams, self-care education and behavioural and psychosocial support, are essential.

About the IMPACT Study

Australia lacks national data on the impact of JIA and CRDs on physical and mental health and cost. This information is essential to understand the magnitude and extent of the burden of these diseases, inform policy and planning and guide future health services and targeted research. This deficiency was highlighted in the *2022 Interim Report of the Parliamentary Inquiry into Childhood Rheumatic Diseases* [7] and has been a high priority in JAFA's strategic planning. In March 2023, along with the Australian Paediatric Rheumatology Group and the Australian Arthritis and Autoimmune BioBank Collaboration, JAFA launched the Australian Juvenile Arthritis Registry (AJAR) for 0-24 year-olds with JIA and CRDs.

The IMPACT Study was commissioned by JAFA in 2022 and conducted in 2023 and represents another milestone in JAFA's commitment to measuring the magnitude of the burden of JIA and CRDs on individuals and families, documenting their lived experience, and establishing a baseline for designing and evaluating future interventions.

METHODOLOGY

Aim

The aim of this study was to describe and document the impact of JIA ad CRDs on the lives of affected children and young people and their families with specific regard to:

- Their experience of diagnosis, treatment, healthcare access and interactions
- Their physical and mental health outcomes, social impact, well-being, and quality of life
- The nature and extent of the financial costs associated with treatment and care.

Study design and population

A national online survey was conducted to examine the impact of JIA and related CRDs on Australian children and young people aged 0-25yrs and their families. The survey was made publicly available from February to June 2023 and was promoted nationally through key consumer organisations and paediatric rheumatology services. Survey responses were entered directly into a REDCap database.

326 survey responses were received of which there were 233 completed surveys - 184 on individuals with JIA and 49 on individuals with CRDs.

Ethics

Ethics approval for this study was obtained from The University of Sydney Human Research Ethics Committee (2022/902). Participation in the study was voluntary and consent was assumed by online completion of the survey. Surveys were anonymous with no identifiable information collected.

RESULTS – JUVENILE IDIOPATHIC ARTHRITIS

Demographics

There were 184 completed surveys for individuals with JIA. The survey was completed by 150 mothers, 21 fathers, 3 carers and self-completed by 10 of 17 young adults (18-25 years) with JIA.

Of the 184 respondents, 23 were aged 0 to less than 5, 73 were aged 5 to less than 12, 71 were aged 12 to less than 18, and 17 were aged 18 to 25 years.

The average age of the 184 individuals with JIA was 12 years (SD=5), 67% were female, 82% Australian/ European, and 75% resided in major cities (*Table 1*). Participants were evenly spread over socioeconomic quintiles and 60% had private health insurance of which 98% were family policies.

Table 1: Demographic characteristics of participants

Demographic characteristics	Total (N = 184)
Age: Mean (SD)	11.7 (±5.1)
Gender	
Male	60 (32.6%)
Female	124 (67.4%)
Ethnicity	
Australian/European	150 (81.5%)
Aboriginal /Torres Strait Islander	6 (3.3%)
Asian	15 (8.2%)
Middle Eastern	8 (4.3%)
Other	5 (2.7%)
[*]SEIFA Quintiles	
1 - Most disadvantaged	27 (14.7%)
2	32 (17.4%)
3	40 (21.7%)
4	34 (18.5%)
5 - Least disadvantaged	51 (27.7%)
[†]Remoteness	
Major city	138 (75.0%)
Regional	46 (25.0%)
Remote	0 (0.0%)

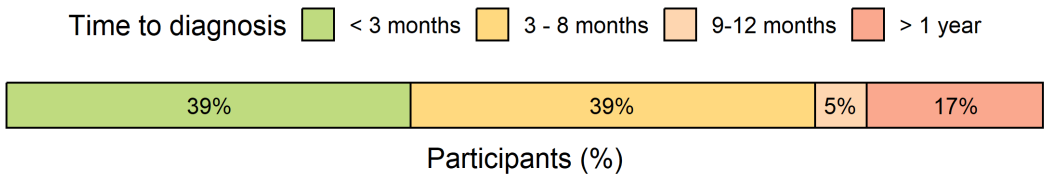
[*]Index of Relative Socio-economic Disadvantage [8],
[†]Remoteness Index of Australia Plus (ARIA+) by postal area[9]

Diagnosis

Time to diagnosis

The average age of JIA symptom onset was 5 years. The average time from symptom onset to diagnosis was 11 months. In young adults, the time from symptom onset to diagnosis was 19 months. 39% of participants were formally diagnosed in the 3 months after actively seeking help but 17% waited more than a year for a formal diagnosis (
Figure *1*). 48% of children aged <5 years were diagnosed within 3 months compared with 29% of those now aged 18-25 years.

Figure 1: Time to diagnosis from actively seeking help



Health professional consultation before diagnosis

An average of 2.3 health professionals were seen before diagnosis. 43% of participants saw an emergency room doctor prior to diagnosis. This was more common in children aged under 12 years (70%) compared with children aged 12 years or older (25%). In 77% the diagnosis was made by a paediatric rheumatologist with 9% diagnosed by a paediatrician.

Treatment and Care

Medications

In the 12 months preceding the survey, 97% of participants had taken some form of medication for their JIA with 68% taking three or more medications.

Almost three-quarters had taken a *csDMARD*, of which Methotrexate was the most common (96%). Over half (53%) had taken a *bDMARD*, of which Adalimumab was the most common (68%). Use of DMARDs increased with age.

Nearly three-quarters took a NSAID. For corticosteroid use, 38% took an oral formulation, 45% had injections and 4% an infusion (**Error! Reference source not found.**). The use of corticosteroid injections was almost double among children aged less than 12 years compared to older children.

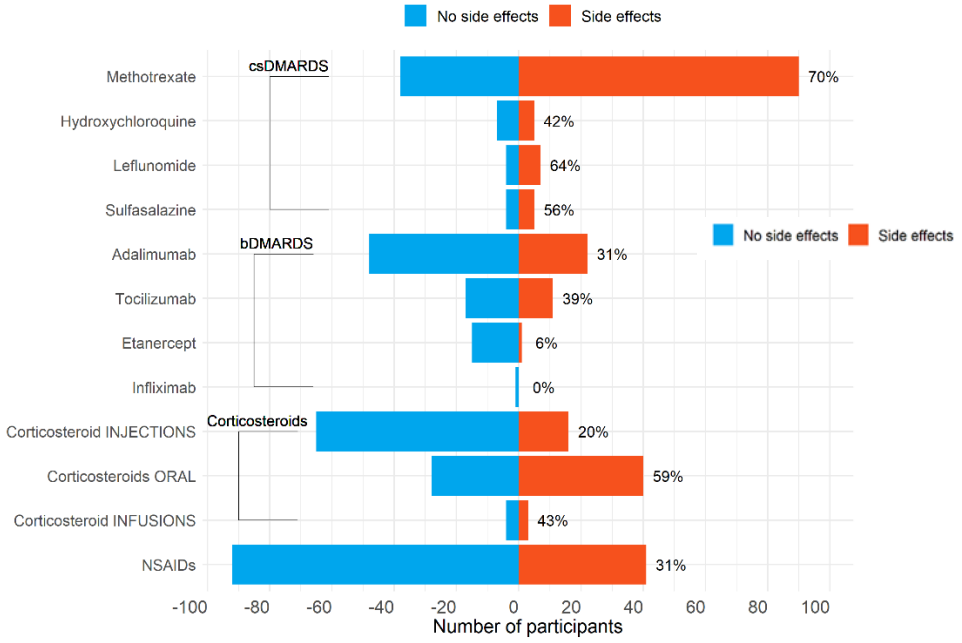
Table 2: Medications taken in the last year

Medication	Total (N = 184)
Taking medications	179 (97.3%)
csDMARDS	
Any	135 (73.4%)
Methotrexate	129 (70.1%)
Hydroxychloroquine	12 (6.5%)
Leflunomide	11 (6.0%)
Sulfasalazine	9 (4.9%)
bDMARDS	
Any	98 (53.3%)
Adalimumab	70 (38.0%)
Tocilizumab	28 (15.2%)
Etanercept	16 (8.7%)
Infliximab	1 (0.5%)
tsDMARDS	
Tofacitinib, Upadacitinib, or Baricitinib	9 (4.9%)
Anti-inflammatories	
NSAIDs	135 (73.4%)
Corticosteroid INJECTIONS	82 (44.6%)
Corticosteroids ORAL	69 (37.5%)
Corticosteroid INFUSIONS	7 (3.8%)

Medication side effects

The occurrence and types of side effects reported by medication are shown in Figure 2. Overall, 72% experienced side effects from medications. Methotrexate had the highest rate of side effects (70% of users), mostly gastrointestinal symptoms and general malaise. 59% of oral corticiosteroid users experenced side effects.

Figure 2: Number of participants with and without side effects by medication

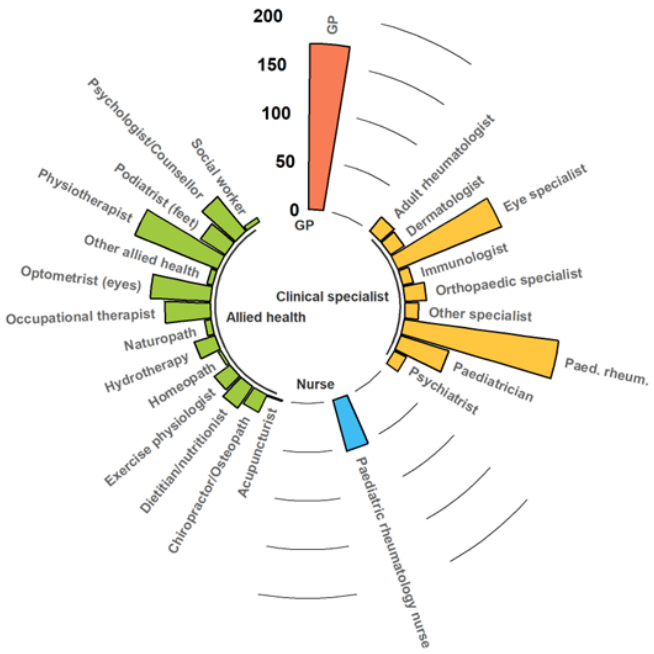


Health professional visits

Health professionals seen most in the past 12 months included GPs (92%), paediatric rheumatologists (87%), ophthalmologists (63%) and physiotherapists (50%). On average, each participant saw 5.6 health practitioners - 1 GP, 2.3 clinical specialists, and 2.3 allied health specialists. During the last 12 months, participants visited health professionals on average 25 times - 5 GP visits, 8 clinical specialist visits, 11 allied health professional visits and 1 specialist nurse visit (Figure 3).

Some participants would have liked to but were unable to see a health professional - physiotherapist (18%), exercise physiologists (15%), psychologists/counsellors (14%), occupational therapists (12%); and access to hydrotherapy (20%). Cost was the most common barrier.

Figure 3: The number of participants seeing each type of health professional over the last 12 months



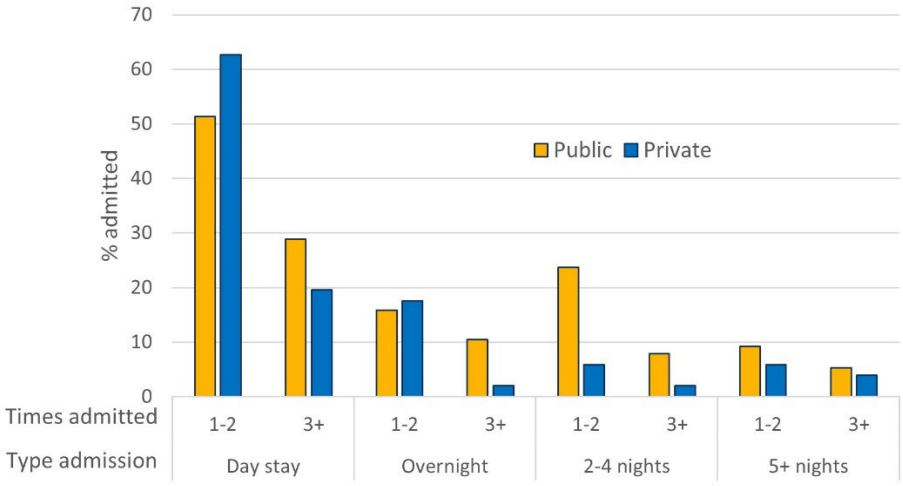
Medical tests

Almost all (97%) of the participants had at least one test in the past 12 months. The most common were blood test (95%) and eye examinations (78%) with participants having an average of 4 blood tests and 3 eye examinations in the past 12 months.

Hospitalisations

In the past 12 months, 56% of participants had at least one hospitalisation - public hospital (28%), private hospital (15%) or both (13%). Of those, 80% had at least one day-stay admission. Admissions of 2-4 nights were more common in public than private hospitals (26% vs 8%) (Figure 4). On average, children with JIA had 2 (SD=4) hospital admissions per year. The commonest reasons for admission of one or more nights were for pain/inflammation (41%) followed by bacterial or viral infections (38%).

Figure 4: Public and private admissions in the past 12 months by number and type

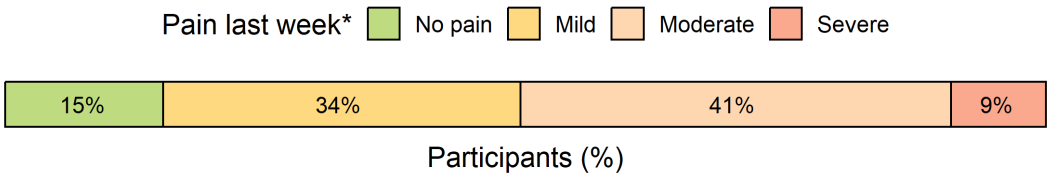


Physical, Emotional and Social Impact

Pain

85% of participants experienced pain in the last week - severe (9%), moderate (41%), mild (34%). Only 15% experienced no pain (Figure 5). There were no significant differences across age categories.

*Figure 5: Pain rating over the last week**

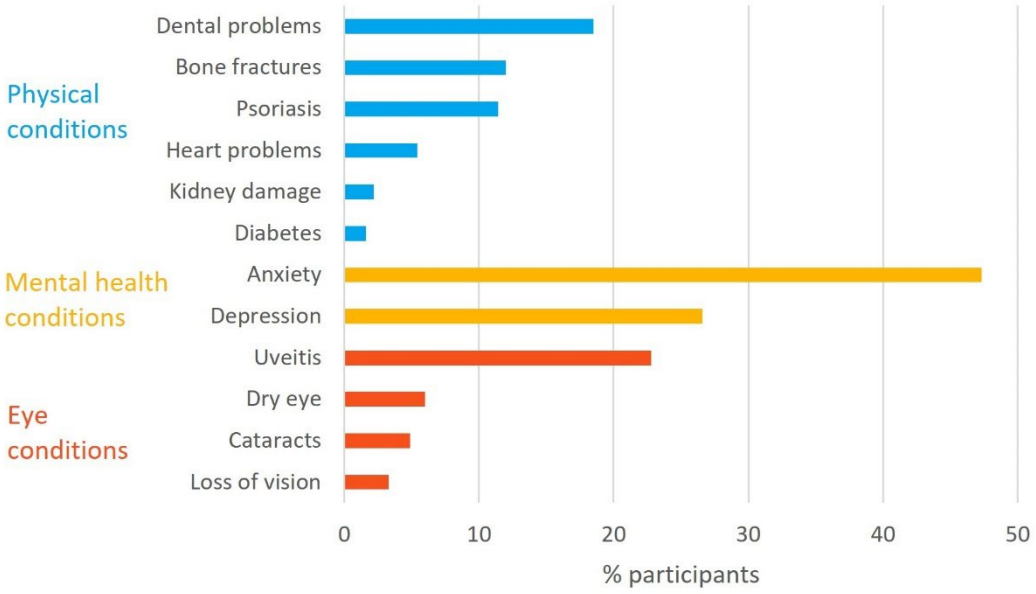


**Participants were asked to rate their pain by sliding the mark on a Numeric Rating Scale where 0 indicates no pain and 10 indicates the worst pain possible)*

Health conditions

The greatest impact of JIA was on mental health (53%), most commonly anxiety, followed by eye conditions (one-third), mostly related to uveitis (Figure 6).

Figure 6: Physical and mental health conditions related to JIA

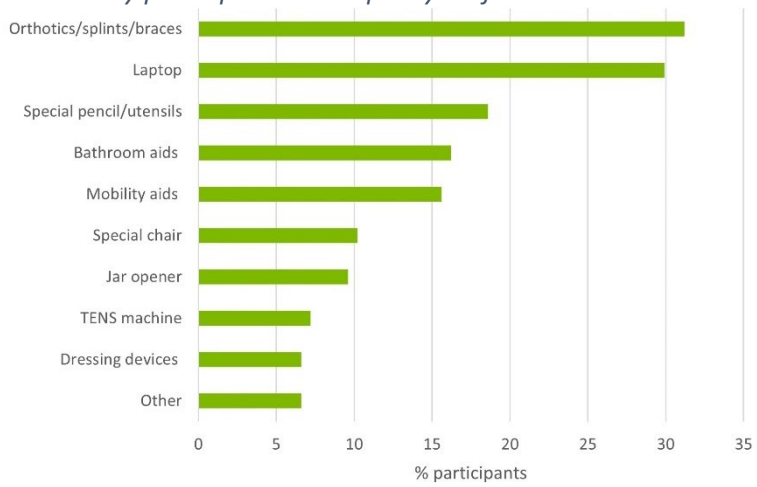


"I have been in a flare for months and medications aren't working for me. So I have put many things on hold, and I am unsure of I'll be able to go back to them because my pain needs to reduce before I can do that. Waiting to see if new medications will work is exhausting. Also taking two immunosuppressant medication has really impacted my immune system and I have been getting every possible infection. So I have been sick a lot too, which is hard ."

Physical aids and devices

31% required orthotics, splints or braces and 46% required aids to assist with daily living (Figure 7).

Figure 7: Aids/devices used by participants in the past year for their JIA



Child employment and education

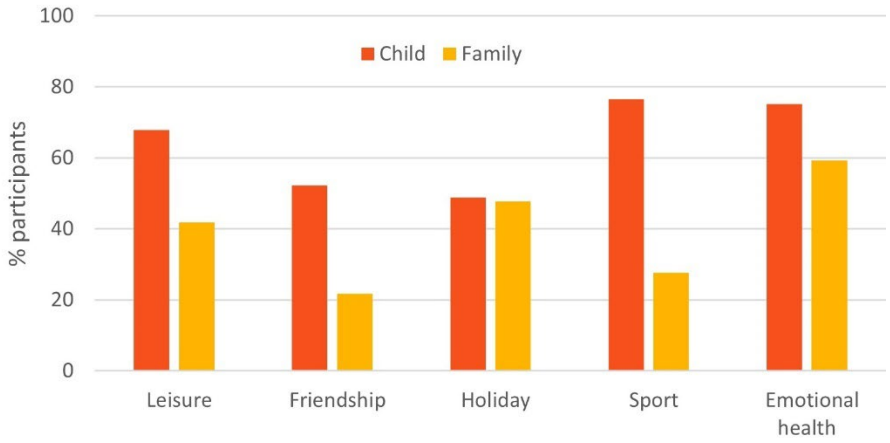
Of the 157 children attending school, 67% indicated that JIA had a moderate to high impact on their education resulting in participants missing an average of 2.6 days of school per month which equates to each child missing 12% of their total annual school time.

29 (16%) participants in the older age groups undertook paid employment in the past year, mostly casual work. Of these, 69% indicated there were days they could not go to work because of their JIA.

Social/emotional impact on the child and families

JIA had a high social impact on children and families. Emotional health was impacted in 75% of children and 59% of families, ability to participate in leisure activities impacted 68% of children and 42% of families and holidays in nearly half. For children, sport was impacted in 77% (Figure 8).

Figure 8: Impact of JIA on participant and family



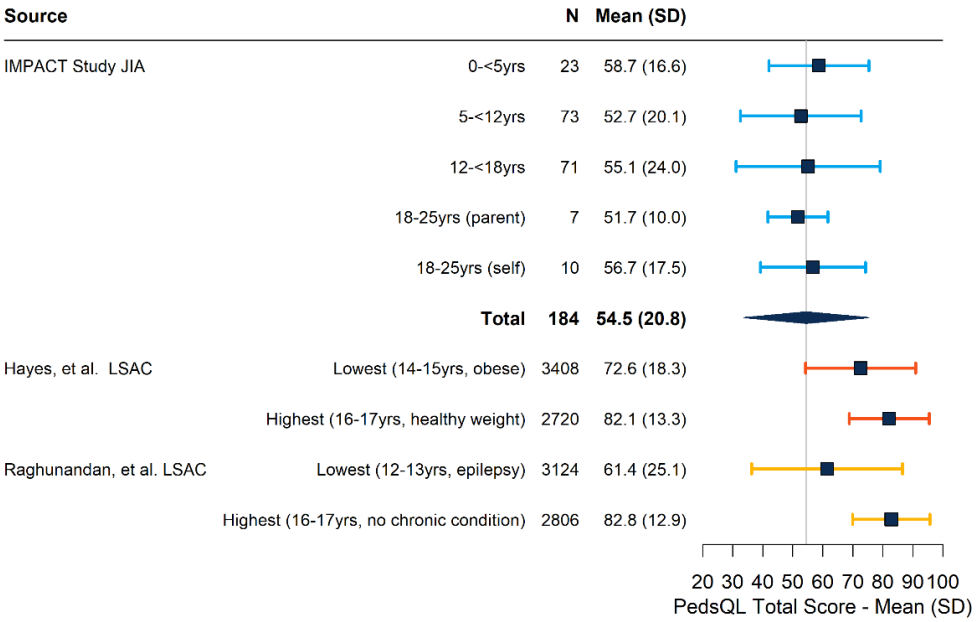
"Made me realise how much the arthritis impacts our life. Particularly our travel, the activities we can do together as a family."

Quality of Life

PedsQL

The average PedsQL quality of life score[10] in individuals with JIA was 54.5. This is considerably lower than comparative Australian benchmarks - healthy weight adolescents (82.1) and those living with obesity (72.6)[11] (Figure 9). Our respondents with JIA also had lower scores than for 12-13 year-old children with epilepsy (61.4) (Figure 9) and type 1 diabetes (77.1)[12].

Figure 9: PedsQL total score for individuals with JIA and comparative Australian benchmarks

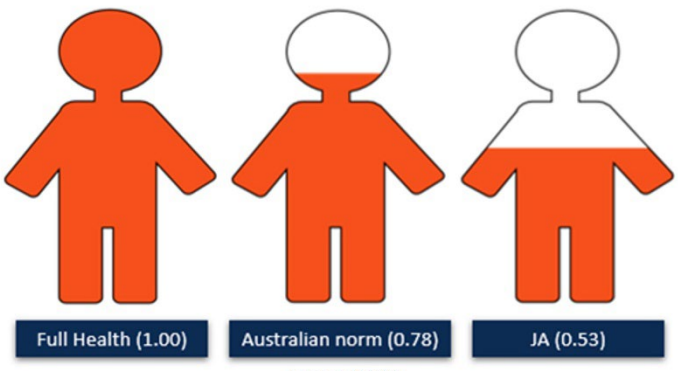


There were also differences between self-rated and parent rated young adult scores (18-25yrs), where parents tend to rate emotional, social, and school functioning lower than self-rated young adults. Conversely, self-rated young adults rated their physical functioning lower than their parents.

Child Health Utility (CHU9D)

Quality of Life as measured by the Child Health Utility (CHU9D)[13] score was 0.53 which was considerably lower than the average CHU9D of 0.78 for the Australian population norm for adolescents aged 11-17 years[14]. A 2015 study of Australian community-based adolescents aged 11-17 years reported an average CHU9D of 0.75 for those with long-term disability, illness or medical condition[15], indicating a much lower Quality of Life in individuals with JIA.

Figure 10: Child Quality of Life (CHU9D)



Le et al (2021)

Financial Impact

Total average annual cost was AUD 28,688 per participant for government and out of pocket costs.

Costs to government

The average annual healthcare cost to the government for JIA was estimated at AUD 24,396 per participant in 2022 Australian dollars. This comprised AUD 12,771 (SD=31,958) for hospitalisations, AUD 7,169 (SD=8,338) for DMARDS and oral corticosteroids, AUD 2,779 (SD=2,833) for health professional visits and AUD 1,677 (SD=721) for medical tests. The highest health professional costs were specialist visits (AUD 962, SD=1,007) and allied health (AUD 1,335, SD=1,870). The highest hospitalisations costs were for injections and infusions (AUD 5,084, SD=8,813) and pain, inflammation and investigations (AUD 5,600, SD=27,250).

Government costs related to disability or other benefits could not be calculated and are therefore not included in these estimates.

Out of pocket costs

Total out of pocket annual costs related to JIA were estimated at AUD 4,292 (SD=5,293) per participant in 2022 Australian dollars (Table 3). The highest cost categories were visits to health professionals AUD 1,347 (SD=1,889), followed by transport and accommodation costs, AUD 781 (SD=1,509).

Table 3: Estimated mean (SD) annual out-of-pocket costs related to JIA per participant in 2022 Australian dollars (AUD)*

			Mean (SD) N = 164
Total out of pocket costs			4,292 (5,293)
Medications	*Mean (SD)*	**Transport**	*Mean (SD)*
Prescription medications	411 (658)	Transport costs (including fuel, public transport, parking)	563 (856)
Non-prescription medications	221 (463)		
Health professional visits		**Accommodation**	
General Practitioner	196 (474)	Accommodation associated with JIA related expenses	218 (653)
Specialists	718 (982)		
Allied Health Professionals	433 (831)		
Hospitalisations, medical tests, and ambulance		**Amount saved**	
Hospitalisations	220 (651)	Due to good will of family/friends (e.g., donations, food, accommodation, etc)	101 (435)
Medical Tests (e.g., X-rays, MRI)	227 (599)		
Ambulance Services	57 (340)		
Home and childcare		**Other costs**	
Home and childcare assistance	308 (780)	Other	115 (509)
Medical equipment, special aids, dietary requirements		*As the out-of-pocket costs were measured in ranges: $0,$1-$100,$101-$200,$201-$500,$501-$1000,$1000+, to estimate the mean (SD) costs we have applied the middle of the range, except in the case of $1000+ where $2500 is applied.	
Medical equipment, supplies	107 (392)		
Special aids/clothing	244 (594)		
Special foods/dietary requirements/supplements	154 (440)		

Parental employment

Approximately 80% of those who completed the survey were living with a partner and had a post-secondary school qualification. Over three-quarters had a household income above the national median annual household income of $92,040 (ABS Census 2021).

75% of respondents completing the survey were employed (41% full-time, 34% part-time), 9% had casual employment and 13% were unemployed. Of the unemployed, one-third stated they had the daily task of running a household and 39% were unable to perform paid employment due to their child's health problems. For the employed, 40% indicated their child's condition had impacted their employment in the last 12 months, 60% had taken paid leave days because of their child's JIA, while 30% had reduced their working hours by an average of 12 hours per week to accommodate their child's illness. Nearly 70% had to make flexible working arrangements. Only 5% stated their child's illness had not impacted their employment.

Lost income due to reduced employment or unemployment was not included in financial impact.

Benefits received

The most common support received by families were the carer's allowance (26%), National Disability Insurance Scheme (17%) and Isolated Patients Travel and Accommodation scheme (10%). Of note, up to 35% reported they could not access specific government support and allowances due to challenges related to the application process (too onerous, no support from health professionals, too expensive to get referral letters), were ineligible (not 'sick' enough, making more than the financial threshold, diagnosis not recognised), or were not aware of the benefit. Many stated the financial income threshold for a benefit was too low.

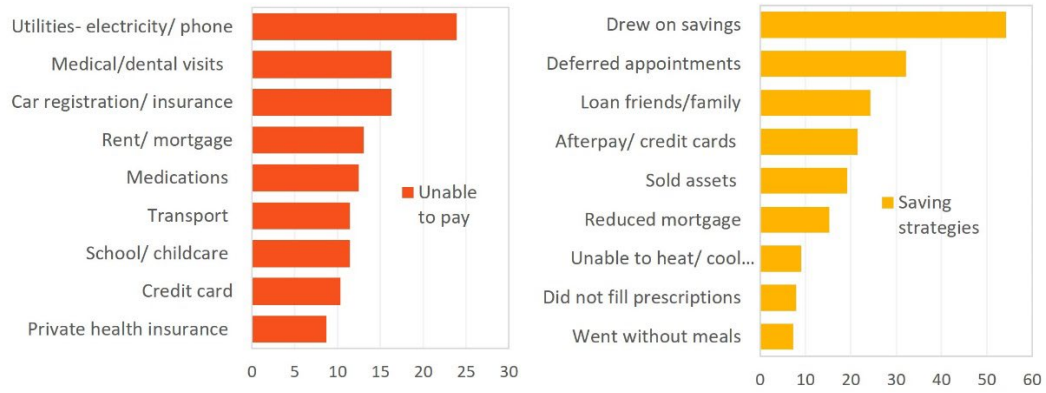
> *"NDIS requires us to spend $2000+ on reports for access which is not guaranteed. We needed to choose to spend that money on either reports or medical appointments."*

Financial hardship

Almost half (48%) of respondents indicated they were in financial hardship over the last 12 months and could not pay for common household expenses or healthcare costs. Of those, 49% were unable to pay rent or mortgage on time, 34% unable to pay for medical appointments or tests, and 34% unable to pay car registration or insurance on time (Figure 11).

Most respondents (76%) used at least one strategy to meet living expenses over the last 12 months. Of those, 68% drew on accumulated savings, 43% deferred appointments, and 30% sought financial assistance from family or friends (Figure 11). In the context of the current general financial hardship, a recent national survey in February 2023 found that 23.1% of Australians were financially stressed[17], indicating a greater burden in JIA families.

Figure 11: Respondents unable to pay and those using cost saving strategies



RESULTS – CHILDHOOD RHEUMATIC DISEASES

Demographics

There were 49 completed surveys for individuals with CRD. The survey was completed by 42 mothers, 5 fathers, 1 carer and self-completed by 1 young adults (18-25 years) with CRD.

Of the 49 respondents, 19 were aged 5 to less than 12, 26 were aged 12 to less than 18, and 4 were aged 18 to 25.

The average age of individuals with CRDs was 13 years (SD=5), 60% were female, 76% Australian/European, and 72% resided in major cities (Table 4).

Participants were more likely to be from least disadvantaged areas[8] and 56% had private family health insurance. There were no statistically significant differences in demographic characteristics by age group.

Table 4: Demographic characteristics of participants

Demographic characteristics	Total N = 49
Age	
Mean (SD)	12.9 (±4.3)
Gender	
Male	21 (42.9%)
Female	28 (57.1%)
Ethnicity	
White/European	39 (79.6%)
Aboriginal/Torres Strait Islander	2 (4.1%)
Asian	3 (6.1%)
Middle Eastern	3 (6.1%)
Other	2 (4.1%)
***SEIFA Quintiles**	
1 - Most disadvantaged	4 (8.2%)
2	11 (22.4%)
3	10 (20.4%)
4	8 (16.3%)
5 - Least disadvantaged	16 (32.7%)
†Remoteness	
Major city	35 (71.4%)
Regional	12 (26.5%)
Remote	1 (2.0%)

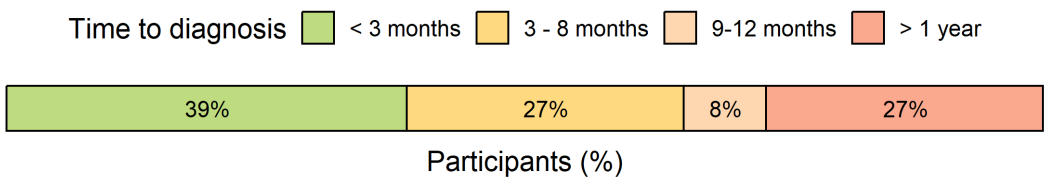
*Index of Relative Socio-economic Disadvantage by participant's postal area[8], †Remoteness Index of Australia Plus (ARIA+) by postal area[9]

Diagnosis

Time to diagnosis

The average age of CRD symptom onset was 6.2 years. The average time from symptom onset to diagnosis was 14 months, with 27% waiting more than a year for a formal diagnosis (Figure 12). Participants saw an average of 2.7 health professionals prior to diagnosis with the commonest being a GP (90%), emergency room doctor (45%) or paediatrician (35%).

Figure 12: Time to diagnosis of CRDs



Treatment and Care

Medications

In the past 12 months, 98% had taken a medication for CRD with 67% taking three or more medications.

71% had taken a csDMARD, with Methotrexate (57%) the most common. 43% had taken a bDMARD, with Adalimumab (16%) and IVIG (14%) being the most common. Nearly half were taking a NSAID and 57% an oral corticosteroid, with minimal use of corticosteroid injections (8%) or infusions (18%) (Table 5).

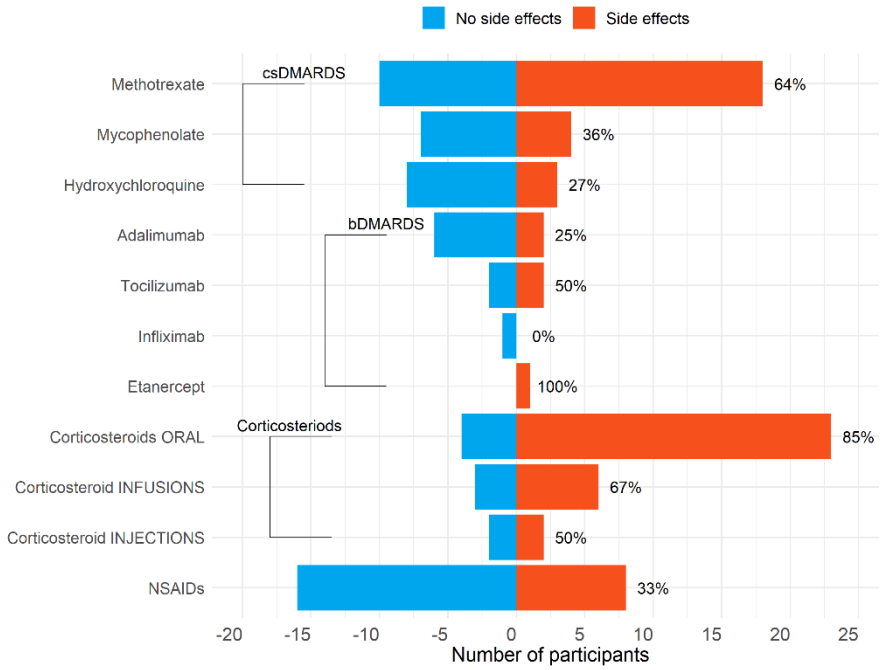
Table 5: Medications taken in the last year

Medication	Total (N= 49)
Taking medications	48 (98.0%)
csDMARDS	
Any	35 (71.4%)
Methotrexate	28 (57.1%)
Hydroxychloroquine	11 (22.4%)
Mycophenolate	11 (22.4%)
bDMARDS	
Any	21 (42.9%)
Adalimumab	8 (16.3%)
IVIG	7 (14.3%)
Tocilizumab	4 (8.2%)
Etanercept	1 (2.0%)
Infliximab	1 (2.0%)
Other bDMARD	5 (10.2%)
tsDMARDS	
Any	1 (0.5%)
Anti-inflammatories	
NSAIDS	24 (49.0%)
Corticosteroids ORAL	28 (49.0%)
Corticosteroids INFUSION	9 (18.4%)
Corticosteroids INJECTION	4 (8.2%)
Other	24 (49.0%)

Medication side effects

Overall, 57% experienced side effects from medications with 85% of oral corticosteroids users and 64% of methotrexate users experiencing side effects (Figure 13).

Figure 13: Participants with and without side effects by medication



Health professional visits

Health professionals seen most in the past 12 months included GPs (92%), paediatric rheumatologists (82%), paediatrician (51%), physiotherapists (49%) and ophthalmologist (43%). On average, each participant saw 6.4 health practitioners - 1 GP, 2.7 clinical specialists and 2.7 allied health specialists. During the last 12 months, participants visited health professionals on average 26 times - 4 GP visits, 9 clinical specialist visits, 11 allied health visits and 2 specialist nurse visits.

Over half (53%) of participants would have liked to but were unable to see a health professional - physiotherapist (15%), dermatologist (13%), exercise physiologists (13%) and podiatrist (13%). Cost was the most common barrier.

Medical tests

91% of participants had at least one test in the past 12 months. The most common were a blood test (92%), eye examinations (55%), XRay (45%) and MRI (40%). Participants had an average of 5 blood tests, 2 eye examinations, 2 XRays and 2 MRIs.

Hospitalisations

In the past 12 months, 57% of participants had at least one hospitalisation, mostly at a public hospital (81%). Of those admitted, 92% had at least one day-stay admission. On average, children with CRDs had 4 (SD=6) hospital admissions per year. The most common reasons for hospitalisations of one or more nights were investigation for pain/inflammation (40%) followed by infection (30%).

Physical, Emotional and Social Impact

Pain

75% of participants experienced pain over the last week - severe (8%), moderate (32%), mild (35%), while 25% experienced no pain.

Health conditions

The greatest impact of CRDs was on mental health (55%), mostly commonly anxiety. 29% report eye problems (10% uveitis and 10% loss of vision) and 22% dental problems. Another 37% experienced a range of other physical health problems.

Physical aids and devices

13% of participants required orthotics, splints or braces and 33% required specific aids to assist with daily living such as special laptop, utensils and mobility aids.

Child education

74% of children attending school indicated their CRD JIA had a moderate to high impact on their education resulting in participants missing an average of 3.1 days of school per month which equates to each child missing 15% of their total annual school time.

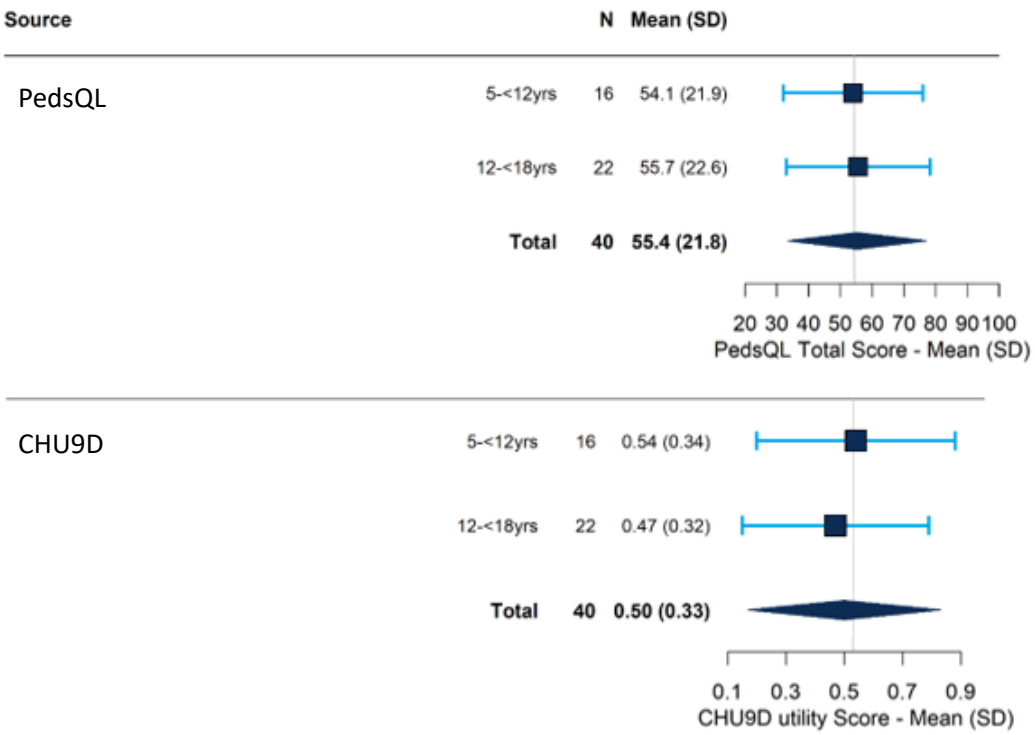
Social and emotional impact on the child and family

CRDs had a high social impact on children and families. In children, emotional health was impacted in 85%, ability to participate in leisure activities in 83%, holidays in 58% and sport in 83%. In families, emotional health was impacted in 73% and holidays in 44%.

Quality of Life

Quality of life scores of CRD participants were very low – the average PedsQL score was 55.4 and the Child Health Utility (CHU9D) score was 0.50 (Figure 14).

Figure 14: Quality of Life scores for CRD participants



Financial Impact

Total average annual cost was AUD 35,368 per participant for government and out of pocket costs.

Costs to government

The average annual healthcare cost to the government for CRDs was estimated at AUD 31,189 per participant in 2022 Australian dollars. This comprised AUD 22,027 (SD=48,256) for hospitalisations, AUD 4,642 (SD=6,073) for medications, AUD 2,922 (SD=2,419) for health professional visits and AUD 1,598 (SD=955) for medical tests. The highest health professional costs were specialist visits (AUD 1027, SD=916) and allied health (AUD 1,460, SD=1,650). The highest hospitalisations costs were for injections and infusions (AUD 9,465, SD=13,182) and pain, inflammation and investigations (AUD 11,066, SD=40,976).

Government costs related to disability or other benefits could not be calculated and are therefore not included in these estimates.

Out of pocket costs

Total out of pocket annual costs related to CRDs were estimated at AUD 4,179 (SD=4,533) per participant in 2022 Australian dollars. The highest cost categories were prescription medications (AUD 593, SD=818), visits to specialists (AUD 463, SD=792) and transport costs (AUD 487, SD=769).

> *"We are a single income family. We are constantly told that $144k annual salary is enough for a family of 4 living in Sydney AND we have 2 children, 1 is living with an incurable disease that affects every aspect of our lives 24-7."*

Parental employment

76% of respondents were living with a partner and 84% had a post-secondary school qualification. Two-thirds had a household income over the national median annual household income of $92,040 (ABS Census 2021).

Of respondents, 84% were employed (44% full-time, 40% part-time) and 11% were unemployed. For those employed, only 10% stated their child's illness had not impacted their employment in the last 12 months. Of those impacted, 51% had taken paid leave days, 28% had reduced their working hours by an average of 10 hours per week, and 61% had made flexible working arrangements because of their child's CRD.

Lost income due to reduced employment or unemployment was not included in financial impact.

Benefits received

The most common support received by families were the Isolated Patients Travel and Accommodation scheme (20%), National Disability Insurance Scheme (17%) and carers' allowance (12%). Of note, up to 55% reported they could not access specific government support and allowances due to challenges related to the application process. This particularly applied to the NDIS.

Financial hardship

Almost half (45%) of respondents indicated they were in financial hardship over the last 12 months and could not pay for common household expenses or healthcare costs. Of those, 19% were unable to pay for medical appointments or tests and 19% were unable to pay rent or mortgage on time. Most respondents (69%) used at least one strategy to pay for living expenses over the last 12 months. Of those, 41% drew on accumulated savings, 43% deferred appointments, and 30% sought financial assistance from family or friends.

> *"I've used all my sick and holiday pay and then I have to take leave without pay. I can't pay for my car payments. I have to rely on my parents and that puts a financial impact on them. I can't get a Medical Benefits card and need to pay full price on medication which is expensive. I had COVID 3 times and paid $100 each time for the antiviral medication. I couldn't work and was on unpaid leave."*

PRIORITIES FOR FUTURE RESEARCH

Respondents were asked about concerns related to their or their child's health and well-being. As illustrated in Figure 155, their main concerns focussed on the future, pain, side effects, flares, and long-term health.

Figure 15: Concerns and anxieties related to JIA and CRDs

Respondents were also asked to prioritise their three top areas for research. There was general similarity for JIA and CRD respondents.

The main focus areas included:

- long-term health impact
- medication use - side effects and long-term effectiveness
- physical impact - pain, fatigue, flares

These priorities were consistent across age groups except for the young adults with JIA who prioritised psychological impact, long-term health impact and minimising costs.

"Wondering how JIA will affect my body long term, what to expect through my late twenties and beyond and impact during pregnancy later on.

Ability to keep up at work and manage fatigue."

"I have aids for her cutlery, and tubing for hand-held items, I give her heat packs etc as gifts so she will have plenty. But she can't cut vegetables- so another life skill that concerns me.

I tried full time work at the beginning of the year but for appointments etc I've gone back to part time."

COMMENTARY

The IMPACT Study provides important new evidence and insights on the extent of the burden of juvenile idiopathic arthritis and childhood rheumatic diseases on affected individuals, their families, and society more broadly.

The highlights of the IMPACT Study include:

- Unacceptable **delays in diagnosis** from time of symptom onset - averaging 11 months for JIA and 14 months for CRDs. Time to diagnosis has not improved compared to that reported in Australia 25 years ago. There is an ongoing lack of awareness of JIA/CRDs among health professionals and the broader community fueled by widespread perceptions that *"kids don't get arthritis"* and *"it's just growing pains".*

- Quantifying the **physical, mental and emotional impact and stress** on individuals and families which prevent and disrupt everyday activities which we take for granted.

- **Medication side effects** are very common, especially with Methotrexate. While DMARDs have had considerable beneficial effects in managing these diseases and reducing their physical consequences, side effects remain challenging. The advent of oral tsDMARDS is very welcome, especially as access and availability is set to increase.

- **Time of missed school** amounting to 12% for JIA and 15% for CRDs of total annual school time. This magnitude of lost educational opportunity is known to have a significant negative impact on school performance and future independence and productivity, on interaction and friendship with peers, and participation in sport and other school activities.

- **Quality of life** – children and young people with JIA and CRDs have a surprisingly poor quality of life - 0.53 for JIA and 0.50 for CRDS. This is considerably lower than the Australian norm for children and young people (0.78) and lower than scores for other comparable chronic diseases.

- **Financial burden** – the cost to government and individuals and families demonstrates the high annual costs of JIA (2022 AUD 28,688) and CRDs (2022 AUD 35,368). Hospitalisation costs for JIA (2022 AUD 12,771) and CRDs (2022 AUD 22,027) are higher than hospitalisation costs for children with type 1 diabetes (2022 AUD 6,451) (unpublished data, Nassar). The average annual healthcare cost to the government per child was also considerably higher for children with JIA (2022 AUD 24,396) and CRDs (2022 AUD 31,189) compared to children with obesity in early childhood (2022 AUD 2,695).[17]

The IMPACT Study data have provided a systematically derived baseline against which services and interventions to enhance the care and support of children and young adults with JIA and CRDs can be designed, delivered and assessed in the future.

POLICY IMPLICATIONS

The Interim Report on the Parliamentary Inquiry into Childhood Rheumatic Diseases tabled in the federal parliament in 2022 by the (then) Standing Committee on Health, Sport and Aged Care raised unprecedented awareness of these diseases, and the historical inequalities between them and other comparable chronic childhood diseases. One of the major constraints on the Inquiry, and for making the case for public investment in JIA and other CRDs, was the almost complete absence of primary data about their prevalence and impact.

The IMPACT Study speaks to the Interim Report and details the first systematically derived, comprehensive analysis of the personal and financial impact of JIA and other CRDs on individuals and families living in Australia. Coming at a time when governments around Australia are increasingly conscious of, and working towards redressing those inequalities, the results of the IMPACT Study provide a sound evidence base to guide planning and decision making.

There appear to be three fundamental interventions that could reduce the identified burden on individuals, their families, and the health system.

1. Earlier diagnosis
Reducing time to diagnosis and referral to treatment is central to improving the outcomes of JIA and other CRDs across the spectrum of impacts and we note that the Australian Government has allocated funding from the 2023-24 budget for a national health professional awareness and early diagnosis program.

2. Access to paediatric rheumatology services
All forms of JIA and other CRDs have in common the need for specialist paediatric rheumatology services provided by multi-disciplinary teams made up of doctors, nurses, physiotherapists, occupational therapists, podiatrists, psychologists, social workers, and ophthalmologists who specialise in uveitis. Access to other specialists may also be required depending on disease subtype and progression. Particular consideration needs to be given to models of care that enhance access for individuals and families living in rural and remote areas.

3. Financial benefits and supports
A proportion of survey participants were clearly struggling to meet additional costs and/or with reduced income due to inability to work. While there are a range of financial benefits and supports in place to provide assistance in such circumstances, consideration should be given to promoting these schemes to those who need them, reducing inconsistencies and costs associated with applying for them, simplifying the application process and reducing response times.

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