

# Caregiver Burden Associated with Paediatric Chronic Pain

## using Data from the Paediatric Electronic Persistent Pain Outcomes Collaboration (PaedePPOC) database.



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### Introduction

- The impact of paediatric chronic pain extends beyond the child, with caregivers likely to experience significant burden across various domains of functioning.
- Caring for a child or youth with chronic pain may impact on the caregiver's psychological wellbeing, social functioning, family functioning, working functioning and with associated financial impacts.
- Many studies have, to date, focused on specific areas of caregiver impact. The Bath Adolescent Pain Parent Impact Scale enables a holistic assessment of multiple potential areas of caregiver impact. No such Australasian data is currently available.
- Relatively little is known about what child or caregiver factors are associated with level of caregiver burden.

### Aims

This multi-centre, retrospective study aimed:

- To investigate the nature and extent of impact of paediatric chronic pain on caregivers of children and youth with chronic pain conditions.
- To determine which factors are associated with increased caregiver burden.

### Methods

**Data source:**  
This study utilised the electronic Persistent Pain Outcomes Collaboration Paediatric Database (PaedePPOC). PaedePPOC questionnaire responses were utilised for patients and caregivers at the time of referral to a paediatric pain service in Australia or New Zealand from 2014 to April 2021.

**Inclusion criteria:**

- Patient age  $\leq$  18 years,
- Pain onset  $>$  3 months,
- At least some caregiver self-report data available in database.

**Exclusion criteria:**

- Patient's pain was cancer-related,
- Data was for a second or subsequent episode of pain at a pain service.

Data from 1,929 families were included in the dataset for analysis.

**Measures** (from PaedePPOC database):

**Child-focused measures**

**Paediatric Quality of Life Inventory (PedsQL)** - caregiver report and self-report

**Functional Disability Inventory (FDI)**- self-report

**Pain Chart** – caregiver report

**Modified Brief Pain Inventory** – self report of current, worst, least and usual current pain in past week.

**Pain history** – caregiver report (duration, origin)

**Caregiver-focused measures**

**Bath Adolescent Pain-Parental Impact Questionnaire (BAP-PIQ)**<sup>1</sup>

**Work Productivity and Activity Impairment<sup>2</sup> Questionnaire (WPAI)** – work absenteeism & perceived productivity lost scores

### Results

**Sample descriptives-patients:**

|              | Patient descriptives | n (%)       |
|--------------|----------------------|-------------|
| Age          | 0-4 years            | 5 (0.3)     |
|              | 5-7 years            | 25 (1.4)    |
|              | 8-12 years           | 537 (29.8)  |
|              | 13-18 years          | 1232 (68.5) |
| Gender       | Female               | 1330 (69.0) |
|              | Male                 | 598 (31.0)  |
| Pain source* | Post-injury          | 357 (18.7)  |
|              | Post-surgery         | 127 (6.6)   |
|              | Illness              | 314 (16.4)  |
|              | No known cause       | 780 (40.8)  |
|              | Other                | 336 (17.6)  |

\* As reported by caregiver prior to Clinic Assessment

**Sample descriptives-caregivers:**

|                   | Caregiver descriptives | n (%)       |
|-------------------|------------------------|-------------|
| Gender            | Female                 | 1680 (88.9) |
|                   | Male                   | 209 (11.1)  |
| Relationship      | Has partner            | 1391 (78.9) |
| status            | Single                 | 371 (21.1)  |
| Employment status | Full-time              | 312 (21.7)  |
|                   | Part-time              | 336 (27.6)  |
|                   | Not employed           | 441 (36.3)  |

**Work-related impact:**  
Caregivers dealing with paediatric chronic pain missed on average 15.31% of required work hours in the past week and incurred a 38.29% loss in work productivity.

Caregivers dealing with paediatric chronic pain experienced significantly greater levels of work **absenteeism** compared with other published data for caregivers of children with:

- Uncontrolled asthma<sup>3</sup> ( $t(693) = 11.51, p<.01$ ),
- Cystic fibrosis<sup>4</sup> ( $t(693) = 4.59, p<.01$ ), and
- Juvenile idiopathic arthritis<sup>5</sup> ( $t(693) = 5.65, p<.01$ ).

Similarly, caregiver work **productivity loss** (associated with paediatric chronic pain) was significantly greater for current sample than the above caregiver samples for children (all  $p$ 's  $<.01$ ).


Caregivers of children with chronic pain in the current sample reported significantly higher work **absenteeism** ( $t(700)=12.63, p<.01$ ) and significantly greater work **productivity loss** ( $t(505) = 19.81, p<.01$ ) than a large-scale study of **adults experiencing pain themselves**.

# Predictors of Caregiver Impact:

DV: Caregiver Negative Psychosocial Impact

|  | B     | Std $\beta$ |
|--|-------|-------------|
| STEP 1   |       |             |
| Worst pain intensity   | 2.75  | 0.17**      |
| Pain duration  | 3.96  | 0.06        |
| <b>Total: <math>R^2 = 0.03</math> F= 11.336*</b>                                 |       |             |
| STEP 2   |       |             |
| Worst pain intensity   | 0.15  | 0.01        |
| Pain duration  | 5.18  | 0.08*       |
| Child physical disability  | 0.24  | 0.10*       |
| Child psychosocial   | -0.50 | -0.31**     |
| School missed last fortnight   | 1.25  | 0.16**      |
| Healthcare utilisation   | 0.15  | 0.06        |
| <b>Total: <math>R^2 = .22</math>; <math>\Delta R^2 = 0.19</math>; F= 35.39**</b> |       |             |

Strongest predictor of caregiver psychosocial functioning was child psychosocial functioning.



DV: Caregiver Work Productivity Loss

|                              | B  | Std $\beta$ |
|------------------------------|--|-------------|
| STEP 1                       |  |             |
| Worst pain intensity         | 3.82                                     | 0.24**      |
| Pain duration                | -7.22                                    | -0.12*      |
| Total                        | $R^2= 0.03$ F= 11.336*                   |             |
| STEP 2                       |  |             |
| Worst pain intensity         | 1.59                                     | 0.10*       |
| Pain duration                | -1.80                                    | -0.03       |
| Child physical disability    | 0.36                                     | 0.15*       |
| Child psychosocial           | -0.04                                    | -0.03       |
| School missed last fortnight | 2.13                                     | 0.29**      |
| Healthcare utilisation       | 0.27                                     | 0.12*       |
| Total                        | $R^2= .23; \Delta R^2= 0.16; F= 20.30^*$ |             |

Caregiver work productivity was most affected by child's days off school.

### Discussion

- Caregivers of children with chronic pain experienced considerable caregiver burden (work-related functioning and psychosocial wellbeing).
- Caregivers of children with chronic pain incurred greater levels of work absenteeism and work productivity loss relative to community-based norms, most other examined caregiver samples, as well as some adult pain patient samples.
- Caregiver psychosocial impact was most strongly predicted by child psychosocial functioning, with weaker significant effects for school absenteeism, child physical functioning and pain condition duration.
- Caregiver work productivity loss was most strongly predicted by school absenteeism, but also the child's level of physical disability, amount of child healthcare appointments, and (longer) pain duration

**Limitations:** The study used a **cross-sectional design**, therefore limiting assumptions of causality. Data collection occurred at the **time of referral** to a Paediatric Pain Service, when families may have been most concerned about their child's pain. **Fewer fathers** completed the surveys and may have been more engaged with their child's pain management than other fathers. The BAP-PIQ lacks **normative data**.

- Future directions:**
- Longitudinal research is needed to assess possible fluctuations in caregiver burden over time, e.g., following the child's treatment.
  - More work is needed on the development and integration of caregiver interventions into pediatric chronic pain programs.
  - Screening caregivers for those at greatest risk of poor psychosocial or work-related functioning may provide opportunities for targeted interventions.
  - Investigation of possible *positive* caregiver impacts associated with caring for a child with chronic pain may be beneficial (e.g., stronger relationships, resilience).
  - Given the limitations of existing measures to assess caregiver impact, there is also a need for qualitative research in this area. (See accompanying poster.)

### References

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