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## **Carer-proxy and child self-reported ratings of pain and quality of life**

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## Carer-proxy and child self-reported ratings of pain and quality of life

### Abstract

The aim of this paper is to examine agreement between carer-proxy reports and child self-report of pain and health-related quality of life. The paper will also examine whether agreement varies with the age and sex of the child.

### Keywords

child, self-reported, quality, ratings, pain, life, carer-proxy

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# Carer-proxy and child self-reported ratings of pain and quality of life

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# Background

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The electronic Persistent Pain Outcomes Collaboration (ePPOC) is an Australasian initiative which aims to improve services and outcomes for people experiencing persistent pain. It is an initiative of the Faculty of Pain Medicine and was established in 2013 with funding from the NSW Ministry of Health.

The key functions of ePPOC are to:

- facilitate the collection of standardised data from pain management services
- analyse and report these data to participating pain services, stakeholders and the broader community
- use the data for benchmarking and quality improvement; and
- promote research into areas of importance in pain management.

While ePPOC has been developed for adults experiencing persistent pain, PaedePPOC addresses the differing requirements of the paediatric pain management sector, allowing collection of data items and assessment tools specific to the needs of children, adolescents and their carers.

Further detail regarding ePPOC and its establishment has been published<sup>1</sup> and is available on the ePPOC website at <https://ahsri.uow.edu.au/eppoc>

## Aims

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The aim of this paper is to examine agreement between carer-proxy reports and child self-report of pain and health-related quality of life. The paper will also examine whether agreement varies with the age and sex of the child.

## Methods

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At referral to a specialist outpatient paediatric pain management service in Australia, children and their carers complete a number of outcome measures, which vary according to the child's age. As part of this dataset, carers and children aged eight years and over complete four pain severity questions based on the Brief Pain Inventory<sup>2</sup>. These questions ask children and carers to rate the severity of the pain now, at its worst, least and usual over the past week. An average pain severity score is computed as the average of the four items. Younger children (aged 5-7 years) complete the Faces of Pain Scale – Revised<sup>3</sup>. Additionally, both carers and children complete the Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales<sup>4</sup> to assess health-related quality of life (HRQoL).

Children in the 5-7 year age group were not included in this analyses due to small numbers. Data for children aged eight and over were included if both the carer and their child completed the pain severity questions and/or the PedsQL, and the child's age and sex were known.

The correlation between carer and child scores was assessed using Pearson product-moment correlations. Exact agreement of child and carer scores was assessed using Intraclass Correlations (ICC: two-way mixed effect, absolute agreement, single measure).

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<sup>1</sup> Tardif H, Arnold C, Hayes C and Eagar K (2017). "Establishment of the Australasian Electronic Persistent Pain Outcomes Collaboration". *Pain Medicine* 18(6): 1007-1018.

<sup>2</sup> Brief Pain Inventory, © 1991. Reproduced with acknowledgement of the Pain Research Group, University of Texas, MD Anderson Cancer Centre, USA

<sup>3</sup> Faces Pain Scale – Revised, © 2001, International Association for the Study of Pain

<sup>4</sup> Pediatric Quality of Life Inventory (PedsQL™), © 1998 JW Varni, Ph.D. All rights reserved.

Consistent with the work of others<sup>5,6</sup>, effect sizes for Pearson’s r were interpreted as small (0.1 to 0.29), medium (0.30 to 0.49) or large ( $\geq 0.50$ ), and ICCs were interpreted as indicating poor agreement ( $\leq 0.4$ ), moderate agreement (0.41 to 0.60), good agreement (0.61 to 0.80), or excellent agreement (0.81 to 1.00).

## Results

Information was provided by seven specialist paediatric pain services in Australia, collected during the period January 2014 to July 2018. Referral questionnaires completed by 1051 carer-child dyads were included in the analysis.

The carers were predominantly the parent or step-parent of the child (98.2%) and female (88.3%). The majority of the children were also female (68.9%). Their average age was 13.4 (SD = 2.4): females 13.7 years (SD = 2.3) and males, 12.8 years (SD = 2.4).

### Pain Severity

Table 1 shows the average carer-proxy and child self-reported scores for pain severity as a function of sex and age group of the child.

<b>Table 1. Carer- and child-reported pain severity by child sex and age group</b>					
	<b>N</b>	<b>Carer report, Mean (SD)</b>	<b>Child report, Mean (SD)</b>	<b>Pearson Correlation*</b>	<b>Intraclass Correlation*</b>
Total group	1013	5.5 (2.0)	5.7 (2.0)	0.81	0.80
Male	315	5.5 (2.1)	5.6 (2.2)	0.86	0.85
Female	698	5.5 (1.9)	5.7 (1.9)	0.78	0.78
8-12 years	407	5.4 (2.1)	5.6 (2.1)	0.79	0.79
13-18 years	606	5.6 (1.9)	5.7 (1.9)	0.82	0.82

Note: only cases where both child and carer complete all four pain severity questions are included.

\*All p values <0.001

On average, children reported higher pain severity compared to that reported by their carer. The correlation between child and carer scores was large for the total group, for male and female children and for both age groups (all r values  $\geq 0.50$ ). Agreement between child and carer scores was good for the total group, for female children and for 8-12 year olds. Agreement was excellent between male children and their carers, and adolescent children and carers.

### Health-related Quality of Life (HRQoL)

Table 2 shows the average carer-proxy and child self-reported scores for HRQoL (as measured using the PedsQL) as a function of sex and age group of the child.

<sup>5</sup> Lifland B E, Mangione-Smith R, Palermo T M and Rabitts J A (2018). “Agreement Between Parent Proxy Report and Child Self-Report of Pain Intensity and Health-Related Quality of Life After Surgery”. *Academic Paediatrics* 18(4): 376-383.

<sup>6</sup> Varni J W and Burwinkle T M (2006). “The PedsQL as a patient-reported outcome in children and adolescents with Attention-Deficit/Hyperactivity Disorder: a population-based study”. *Health and Quality of Life Outcomes*. DOI: 10.1186/1477-7525-4-26.

<b>Table 2. Carer- and child-reported health-related quality of life (as measured using the PedsQL) by child sex and age group</b>					
	<b>N</b>	<b>Carer report, Mean (SD)</b>	<b>Child report, Mean (SD)</b>	<b>Pearson Correlation*</b>	<b>Intraclass Correlation*</b>
<b>Total PedsQL score</b>					
Total group	1033	45.9 (16.8)	49.1 (17.8)	0.75	0.74
Male	320	46.8 (17.5)	52.1 (18.1)	0.75	0.72
Female	713	45.5 (16.4)	47.7 (17.5)	0.75	0.75
8-12 years	417	47.7 (17.1)	50.7 (17.7)	0.76	0.74
13-18 years	616	44.7 (16.4)	48.0 (17.8)	0.75	0.73
<b>Physical Health</b>					
Total group	1030	37.4 (22.4)	39.5 (22.4)	0.76	0.75
Male	320	39.9 (24.0)	43.4 (24.3)	0.77	0.76
Female	710	36.3 (21.6)	37.7 (21.2)	0.74	0.74
8-12 years	417	38.3 (23.7)	40.7 (23.6)	0.79	0.79
13-18 years	613	36.9 (21.5)	38.6 (21.5)	0.73	0.72
<b>Psychosocial Health</b>					
Total group	1029	50.5 (17.1)	54.2 (18.5)	0.71	0.70
Male	318	50.6 (17.6)	56.7 (18.4)	0.69	0.65
Female	711	50.5 (16.9)	53.1 (18.5)	0.73	0.72
8-12 years	417	52.8 (17.3)	56.1 (18.3)	0.71	0.70
13-18 years	612	49.0 (16.8)	53.0 (18.6)	0.71	0.69
<b>Emotional Functioning</b>					
Total group	1026	46.0 (21.1)	49.8 (22.7)	0.68	0.66
Male	316	47.7 (22.6)	53.4 (23.5)	0.67	0.65
Female	710	45.2 (20.4)	48.2 (22.2)	0.68	0.67
8-12 years	414	46.4 (20.9)	49.6 (22.4)	0.66	0.65
13-18 years	612	45.8 (21.4)	49.9 (22.9)	0.69	0.67
<b>Social Functioning</b>					
Total group	1020	60.7 (21.6)	65.3 (22.8)	0.66	0.65
Male	311	60.1 (21.9)	67.1 (21.7)	0.64	0.61
Female	709	61.0 (21.5)	64.5 (23.2)	0.67	0.66
8-12 years	410	62.0 (21.9)	65.8 (21.8)	0.67	0.66
13-18 years	610	59.8 (21.4)	65.0 (23.4)	0.65	0.64
<b>School Functioning</b>					
Total group	1022	45.0 (22.3)	47.6 (23.0)	0.72	0.71
Male	314	44.2 (22.1)	49.5 (22.3)	0.68	0.67
Female	708	45.3 (22.4)	46.7 (23.3)	0.74	0.74
8-12 years	414	50.0 (22.3)	52.9 (22.1)	0.72	0.71
13-18 years	608	41.6 (21.7)	43.9 (22.9)	0.70	0.70

Note: Higher scores indicate better HRQoL. Total scores are reported where carer and child validly completed the PedsQL. Subscales scores are reported where carer and child validly completed the respective subscale.

\*All p values <0.001.

The mean scores of children were higher than that of their carers, suggesting that children reported better HRQoL compared to the ratings of their carers. The correlation between child and carer scores was large over all domains, for the total group, and by gender and age group (all  $r$  values  $\geq 0.50$ ). Absolute agreement between child and carer ratings was good across all domains, age groups and by sex, with ICC correlation coefficients between 0.61 and 0.79. Agreement was generally higher for the physical compared to psychosocial domains.

## Practice points

- This study shows that overall, and regardless of the child's age or gender, carer reports are a good (but not perfect) proxy for child's pain intensity and health-related quality of life at referral to a pain service. Whilst a child's report should remain the primary source of information, it may be reasonable to substitute a carer-proxy report in situations where the child is unable to complete the assessment tools.
- In the clinical setting:
  - Child and carer reports each provide a unique perspective
  - There will be dyads where carer and child reports diverge, often significantly. Therefore, it remains important that clinicians continue to evaluate the reports of both the carer and their child.
  - Understanding the level of agreement between a child and their carer provides the clinician with insights about the relationship and potential areas to explore further, for example how they communicate with each other around pain, and whether the child feels believed or understood by their carer about their pain. This can then guide clinicians as to where to direct further pain-related education, and facilitate discussions between the child and their carer.
  - A comprehensive paediatric pain assessment should continue to draw on reports and information from a variety of sources including the child, their carer, and thorough clinical assessment of the pain and its impact on life.
- When there are sufficient follow-up outcomes, it will be interesting to compare ratings following treatment to see if there is equivalent level of agreement

# Series List

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No.1 2018: *Normative data for patients referred for specialist pain management in Australia*

No.2 2018: *Normative data for children and adolescents referred for specialist pain management in Australia*

No.3 2018: *Carer-proxy and child self-reported ratings of pain and quality of life*