

A Survey of Caregiver Perspectives on Children's Pain Management in the Emergency Department

Samina Ali, MDCM*[†]; Laura E. Weingarten, MD[‡]; Janeva Kircher, MD[§]; Kathryn Dong, MD[§]; Amy L. Drendel, DO, MS[¶]; Rhonda J. Rosychuk, PhD*[†]; Sarah Curtis, MD*^{†§}; Amanda S. Newton, PhD, RN*[†]

ABSTRACT

Objectives: We explored caregiver perspectives on their children's pain management in both a pediatric (PED) and general emergency department (GED). Study objectives were to: (1) measure caregiver estimates of children's pain scores and treatment; (2) determine caregiver level of satisfaction; and (3) determine factors associated with caregiver satisfaction.

Methods: This prospective survey examined a convenience sample of 97 caregivers (n = 51 PED, n = 46 GED) with children aged <17 years. A paper-based survey was distributed by research assistants, from 2009–2011.

Results: Most caregivers were female (n = 77, 79%) and were the child's mother (n = 69, 71%). Children were treated primarily for musculoskeletal pain (n = 41, 42%), headache (n = 16, 16%) and abdominal pain (n = 7, 7%). Using a 100 mm Visual Analog Scale, the maximum mean reported pain score was 75 mm (95% CI: 70–80) and mean score at discharge was 39 mm (95% CI: 32–46). Ninety percent of caregiver respondents were satisfied (80/89, 90%); three (3/50, 6%) were dissatisfied in the PED and six (6/39, 15%) in the GED. Caregivers who rated their child's pain at ED discharge as severe were less likely to be satisfied than those who rated their child's pain as mild or moderate (p = 0.034).

Conclusions: Despite continued pain upon discharge, most caregivers report being satisfied with their child's pain management. Caregiver satisfaction is likely multifactorial, and physicians should be careful not to interpret satisfaction as equivalent to adequate provision of analgesia. The relationship between satisfaction and pain merits further exploration.

RÉSUMÉ

Objectifs: L'étude a porté sur le point de vue des aidants quant à la prise en charge de la douleur chez les enfants dans un service des urgences pédiatriques (SUP) et dans un service des urgences générales (SUG). L'étude visait à: 1) mesurer l'intensité de la douleur chez les enfants, estimée par les aidants ainsi que le traitement appliqué; 2) déterminer

le degré de satisfaction des aidants; et 3) déterminer les facteurs associés à la satisfaction des aidants.

Méthode: Il s'agit d'une enquête prospective, menée dans un échantillon de commodité de 97 aidants (SUP: n = 51; SUG: n = 46) qui accompagnaient des enfants de moins de 17 ans. Des questionnaires d'enquête sur papier ont été distribués par des assistants de recherche, de 2009 à 2011.

Résultats: La plupart des aidants étaient des femmes (n = 77; 79 %) et, bien souvent, la mère des enfants (n = 69; 71 %). Les enfants étaient traités surtout pour des douleurs musculosquelettiques (n = 41; 42 %), des céphalées (n = 16; 16 %) et des douleurs abdominales (n = 7; 7 %). Le score maximal moyen, indiqué sur une échelle visuelle analogue de 100 mm s'élevait à 75 mm (IC à 95 %: 70-80) et le score moyen au moment du congé était de 39 mm (IC à 95 %: 32-46). Quarante-vingt-dix pour cent des aidants qui ont répondu à l'enquête se sont dits satisfaits (n = 80/89; 90 %); 3 (n = 3/50; 6 %) au SUP et 6 (n = 6/39; 15 %) au SUG ne l'étaient pas. Les aidants qui ont indiqué que la douleur était forte au moment du congé du SU étaient moins susceptibles d'être satisfaits que ceux qui ont indiqué que la douleur était légère ou modérée (p = 0,034).

Conclusions: Malgré la présence d'une douleur persistante au moment du congé, la plupart des aidants se sont déclarés satisfaits de la prise en charge de la douleur chez les enfants. Le degré de satisfaction des aidants est sans doute plurifactoriel, et les médecins devraient veiller à ne pas interpréter la satisfaction des aidants comme l'expression d'une analgésie suffisante. La relation entre la satisfaction et la douleur mérite d'être approfondie.

Keywords: caregiver, satisfaction, parent, emergency, pain, children

INTRODUCTION

Pain is a common reason for seeking health care¹⁻³ and adequate pain management is a basic human right^{4,5}.

From the *Department of Pediatrics, Faculty of Medicine and Dentistry, University of Alberta, Edmonton, AB; †Women and Children's Health Research Institute, Edmonton, AB; ‡Department of Pediatrics, University of Toronto, Toronto, ON; §Department of Emergency Medicine, Faculty of Medicine and Dentistry, University of Alberta, Edmonton, AB; and ¶Department of Pediatrics, Medical College of Wisconsin, Milwaukee, WI, USA.

Correspondence to: Samina Ali, Department of Pediatrics and Emergency Medicine, Edmonton Clinic Health Academy, 11405 – 87 Avenue, Edmonton, AB, T6G 1C9; Email: sali@ualberta.ca

Inadequate pain management in infancy and early childhood can lead to detrimental effects later in life, including fear of medical events, avoidance or overuse of medical care, and heightened sensitivity to subsequent medical care.⁵⁻⁷ Children are at particularly high risk for pain under-treatment, or oligoanalgesia, in the emergency department (ED) setting.^{8,9} Children in the ED receive relatively less analgesia than adults with comparable medical conditions,¹⁰ and younger children receive proportionally less analgesia than do older children.^{7,11} Multiple factors contribute to oligoanalgesia, including health care provider hesitancy to prescribe strong pain medications, and misperceptions that children perceive pain differently than adults.^{4,7,9,12}

It can be difficult to recognize and assess a child's pain in the ED. Health care providers often underestimate that pain,¹³⁻¹⁵ while parents/caregivers (referred to as "caregivers" henceforth) are often considered a valid proxy.^{16,17} This reliance on caregiver feedback persists, even when children are able to speak for themselves.¹⁸⁻²⁰ As their child's primary advocate across all health care settings, caregivers' perspective need to be considered and more clearly understood.²¹⁻²⁴

Recent studies have suggested that the type of ED setting, specifically general (GED) versus pediatric (PED) ED, is associated with how health care providers assess and manage children's pain.^{25,26} It has been shown that there are differential practices for medication choices, frequency and treatment of measurement of pain, and discharge pain treatment advice.^{25,26} Soliciting caregiver perspectives is a first step towards understanding how pain and satisfaction relate to one another. To our knowledge, no study has compared caregiver perspectives across both PEDs and GEDs. Our study objectives were to: (1) measure caregiver estimates of children's pain levels, pain treatment, and experience; (2) determine caregiver level of satisfaction; and (3) determine factors associated with caregiver satisfaction.

METHODS

Study setting and population

This study was conducted at two tertiary care hospitals in Edmonton, Alberta, Canada. The Royal Alexandra Hospital ED sees patients of all ages, had an average annual census of 66,701 patients (of which 4,076 were <17 years of age) during the study period (2009–2011), and was staffed by emergency medicine specialists.

The Stollery Children's Hospital ED only treats children less than 17 years old, had an average annual census of 27,513 during the study period (2009–2011), and was staffed by pediatric emergency medicine specialists. There was research assistant (RA) coverage in the EDs for six to eight hours, approximately three to five days per week (including days, evenings, and weekends), during the study recruitment periods (summer 2009, summer and winter 2010, and all of 2011).

Design

This study was a prospective cross-sectional survey. A convenience sample of 97 families who met the following inclusion criteria participated: caregivers presenting to the ED with children (0 to 17 years) who were treated for acute pain and then discharged home; pain was part of the triage-reported presenting problem; and families could understand spoken and written English. Study data were collected from 2009 to 2011. The University of Alberta Health Research Ethics Board approved this study.

Study variables and measures

For each participating child-caregiver pair, data were collected regarding general demographic characteristics, including the child's age, sex, and presenting complaint, as well as their caregiver's age, sex, and relationship to the child. At the end of their ED visit, caregivers were asked to report pain scores, management provided in the ED, and discharge advice from physicians/nurses. These questions were followed by the American Pain Society Patient Outcome Questionnaire–Modified (APS-POQ-M) (see Appendix A), a validated survey instrument, designed for hospitalized adult patients,²⁷ which has since been used to also document caregiver perspectives of acute pain management.²⁸⁻³⁰ The APS-POQ-M asks caregivers to report several pain scores (maximum and average pain score in the preceding 24 hours, and pain score immediately prior to discharge). A 100 mm Visual Analog Scale (VAS) was used to measure pain, and pain scores were classified into mild (<30 mm), moderate (30–69 mm) and severe (>69 mm), based on the World Health Organization's pain ladder.³¹ The APS-POQ-M also asks caregivers to report on interference with daily activities and perspectives on pain medication in general, and also assesses satisfaction with various aspects of care, including overall pain treatment and nurse/physician

response to their child's pain. The entire survey was pilot tested with five adult caregivers prior to its implementation, in order to ensure face and content validity, as well as sensibility for the newly created questions.

Study protocol

A trained RA approached families prior to ED discharge. Interested caregivers were screened for eligibility, and, if deemed eligible, the RA provided a 10-minute printed questionnaire. Consent was implied through completion of the survey, after the RA verbally explained the purpose of the survey, and provided a written information letter regarding the study purpose and length. Caregivers were free to respond to as many or as few of the questions as they felt comfortable, leading to differential response rates for questions. Surveys were returned, in a sealed envelope, in person to the RA or treating nurse, or mailed back in a self-addressed stamped envelope provided to the caregiver. The health care staff (e.g., treating physicians and nurses) was not aware of the study objectives. A trained RA entered all anonymized data in a secure Microsoft Access database (Microsoft Corporation, Kansas City). A second team member (SA) reviewed 10% of data entered for accuracy.

Data analysis

Statistical analyses were performed using IBM Statistics for Windows, Version 20.0 (IBM Corp., Armonk, NY). Means, standard deviations, and 95% confidence intervals (CIs) were computed for continuous data (e.g., age, VAS), while rates were calculated for categorical data (e.g., sex). Group differences were tested using Student *t*-test (continuous variables) while associations were compared using chi-square or Fisher exact test (categorical variables). A *p*-value <0.05 was considered statistically significant.

RESULTS

Demographic characteristics

Ninety-seven completed surveys were collected (PED = 51/97 and GED = 46/97). Demographic characteristics are shown in Table 1. The caregivers surveyed were mostly mothers (*n* = 69, 71%), fathers (*n* = 18, 19%), and grandparents (*n* = 4, 4%).

Table 1. Child and caregiver demographics (n = 97)

Variable	Total n (%)	Caregiver-Reported Satisfaction		<i>p</i> -value*
		Satisfied	Dissatisfied	
Caregiver Sex				0.552
Male	18 (20)	15 (83)	3 (17)	
Female	71 (80)	65 (92)	6 (67)	
Caregiver Age				0.118
< 30 Years	27 (19)	13 (76)	4 (24)	
30–40 Years	34 (39)	31 (91)	3 (8)	
> 40 Years	37 (42)	35 (95)	2 (5)	
Child Age				0.063
< 2 Years	8 (9)	5 (62)	3 (38)	
2–12 Years	53 (60)	49 (92)	4 (8)	
> 12 Years	27 (31)	25 (93)	2 (7)	
Child Pain Type				0.129
Abdominal	8 (9)	6 (75)	2 (25)	
Musculoskeletal	36 (41)	34 (94)	2 (6)	
Headache	12 (14)	12 (100)	0 (0)	
Other	31 (36)	26 (84)	5 (16)	

*Tests of associations between variable and caregiver reported satisfaction.

Pain severity

Table 2 presents the caregivers' estimation of their child's maximum pain reported in the 24 hours prior to ED arrival, and at ED discharge. Mean maximum pain score recalled by parents in the 24 hours prior to survey administration was severe (75 mm; 95% CI: 70–80), while mean pain score reported at ED discharge was moderate (39 mm; 95% CI: 32–46). Of the 12/85 caregivers who reported their children had severe pain at ED discharge, 50% of these children (*n* = 6) were treated for musculoskeletal injury. Caregivers in the GED were more likely to report a higher maximum pain score in the 24 hours preceding ED visit (*p* = 0.015). There was no statistically significant difference between reported pain scores at discharge from the PED and GED (*p* = 0.658).

ED analgesia and discharge advice

Figure 1 summarizes caregiver recollection of analgesia used in the ED. Eighty-four percent of caregivers reported that their child received pharmacologic pain treatment, with 62% (48/77) receiving pain medication by mouth and 22% receiving it intravenously (17/77). Several caregivers (19/77, 25%) reported use of non-pharmacologic treatments while in the ED, including massage (*n* = 5), music (*n* = 2), and heat (*n* = 2). Caregivers in the PED (*n* = 32) were more likely to report use of oral pain medications than those in the GED (*n* = 16) (*p* = 0.01). There was no statistically significant difference in the use of non-pharmacologic

Table 2. Caregiver reports of children’s ED discharge and maximum pain scores (n = 86)

Variable		Total n (%)	Caregiver-Reported Satisfaction		p-value
			Satisfied	Dissatisfied	
Caregiver Estimate of Pain Score Immediately Prior to ED Discharge	Mild	37 (44)	34 (92)	3 (8)	0.034*
	Moderate	36 (42)	34 (94)	2 (6)	
	Severe	12 (14)	8 (67)	4 (33)	
Caregiver Estimate of Maximum Pain Score in the 24 Hours Preceding Survey Administration	Mild	1 (1)	0 (0)	1 (1)	0.097
	Moderate	20 (23)	19 (95)	1 (5)	
	Severe	65 (76)	58 (89)	7 (11)	

*Statistically significant, with p-values calculated for combined GED + PED.

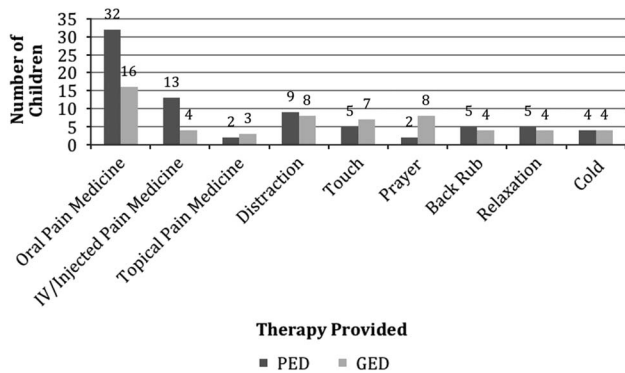


Figure 1. Pain Treatment Reported to be Used During the ED visit. (n = 77 respondents)

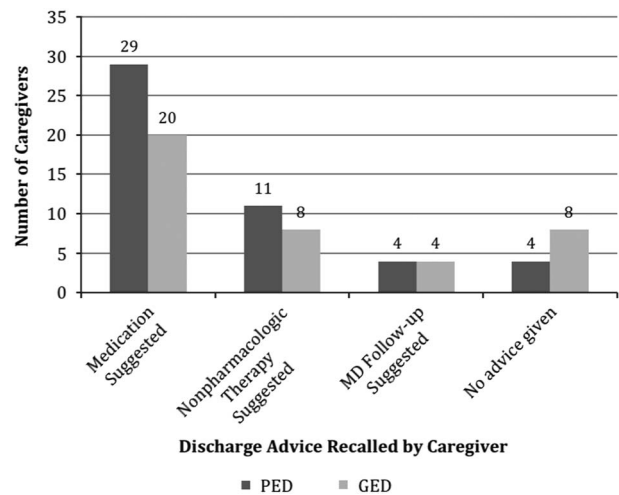


Figure 2. Caregiver Recollection of Nurse and Physician Discharge Advice. (n = 77)

approaches to pain management between sites ($p = 0.757$).

Figure 2 summarizes caregiver recall of discharge advice. Over half of caregivers (49/77, 63%) received discharge advice about pain medication at home; 16% (12/77) reported that they did not receive instructions for pain management at home. There was no statistically significant difference in caregiver recall of discharge advice between sites ($p = 0.066$).

Caregiver perspectives on pain treatment

Table 3 summarizes caregiver perspectives on their child’s pain treatment. Over half of respondents indicated they would *not* request a stronger dose of pain medicine if their child were still having pain (54/96, 57%). More caregivers in the PED felt that team members prioritized pain treatment than caregivers in the GED (PED: 32/51, 63%; GED: 16/44, 36%; $p = 0.013$).

Table 4 outlines caregiver perspectives of their children’s pain treatment. On a five point scale

where 0 = “strongly disagree” and 5 = “strongly agree,” most caregivers disagreed (rating of 0–2) with the statement, “It is easier to put up with the pain than with the side effects that come from pain medicine” (63/93, 68%). Two-thirds of caregivers (60/91, 66%) disagreed with the statement, “Pain medicine cannot really control pain.” Caregivers also disagreed with the statement, “Good patients avoid talking about pain” (81/93, 87%).

Caregiver satisfaction

Nearly 90% (80/89) of caregiver respondents were satisfied with their child’s pain treatment in the ED; there was no statistically significant difference between the PED and GED ($p = 0.270$). Table 1 reports that demographic characteristics, including caregiver age, caregiver sex, child age, and child’s pain location, did not

Table 3. Caregiver perceptions of the ED experience (n = 95)

Question		PED	GED	Both	p-value*
Did a physician/nurse make it clear to you that we consider pain treatment important?	No	19 (37.3%)	28 (63.6%)	47 (49.5%)	0.018†
	Yes	32 (62.7%)	16 (36.4%)	48 (50.5%)	
Was there a time where the medicine didn't work and you asked for something different?	No	50 (98.0%)	41 (93.2%)	91 (95.8%)	0.507
	Yes	1 (2.0%)	3 (6.8%)	4 (4.2%)	
If your child still has pain, would you like a stronger dose of pain medication for them?	No	26 (51.0%)	28 (63.6%)	54 (56.8%)	0.301
	Yes	25 (49.0%)	16 (36.4%)	41 (43.2%)	

*Denotes statistical difference between "yes" answers for each question.
†Statistically significant.

Table 4. Caregiver perspectives on pain treatment*

Statement	Caregiver Response Mean (SD)	Caregiver Response (n)
Pain medicine cannot really control pain.	1.7 (1.7)	91
People get addicted to pain medicine easily.	2.8 (1.6)	92
Good patients avoid talking about pain.	0.9 (1.3)	93
It is easier to put up with pain than with the side effects that come with pain medicine.	1.7 (1.4)	93
Complaints of pain could distract a physician from treating my child's underlying illness.	1.6 (1.5)	92
Pain medicine should be "saved" in case the pain gets worse.	1.7 (1.6)	93
The experience of pain is a sign that the illness has gotten worse.	3.1 (1.4)	91

*Response scale: 0 = do not agree at all; 5 = very much agree.

demonstrate a statistically significant association with caregiver satisfaction ($p = 0.118, 0.552, 0.063, 0.129$, respectively). Reported maximum pain score in the 24 hours preceding survey administration did not have a statistically significant association with caregiver satisfaction ($p = 0.097$). Caregivers who felt their children were in severe pain at the time of ED discharge were less likely to be satisfied than those who felt their children were in mild or moderate pain ($p = 0.034$) (Table 2).

DISCUSSION

Most caregivers reported that their children experienced severe pain (>69 mm) immediately before or

during their ED visit. Although pain scores were lower at ED discharge, nearly half of caregivers reported that their children had moderate to severe pain (30–69 mm) and over 10% reported severe pain at ED discharge. Pain persists well beyond a family's ED departure. It has been recently shown that leaving the ED with suboptimal pain treatment puts children at risk for ongoing oligoanalgesia at home.³⁰ Studies have found that most children treated for musculoskeletal injury have moderate to severe pain 24 hours after ED discharge.^{30,32} Our findings are consistent with this, and reinforce the need for frequent reassessment of analgesia requirements, both during an ED visit and following discharge. Standardized triage pain protocols, clinical pathways, and innovative approaches to discharge education could be ways to address these barriers to children's pain treatment.^{5,6,28}

Our findings highlight discrepancies between caregiver perceptions and current best practices in pediatric pain treatment. Despite persistently high reported pain scores, over half of caregivers would *not* provide a second dose of analgesia if their child were still in pain. Adams-McNeill²⁴ reported similar findings in hospitalized adults, where most reported moderate-severe pain, but 41% did not wish to receive a stronger or additional dose of pain medicine. To the best of our knowledge, no studies have examined caregiver attitudes towards repeat medication dosing or pain reassessment following analgesia, and this could be an essential and mandated step towards improving children's care both in the ED and at home after discharge.³²⁻³⁴

This study also demonstrated that caregivers commonly use non-pharmacologic treatment modalities in the ED, including distraction, touch, and prayer. Despite their relative frequency of use in this study, there is a paucity of literature examining the use of these complementary therapies (particularly touch and prayer) for treatment of acute pain in the ED. Small

studies suggest that music and other modalities may be a valuable adjunct to treat pain in the ED,^{35,36} but definitive evidence is lacking, as is a deeper understanding of parental reasons for utilizing (or not utilizing) these modalities. Further exploration of non-pharmacologic therapies is merited, as they may prove to be minimally invasive, cost-effective ways to improve children's pain and anxiety.

Despite the high caregiver-reported pain scores, caregivers were generally satisfied with their child's ED pain treatment. Similar to our findings, both pediatric²² and adult^{23,24,37} studies have previously reported that pain severity does not determine patient satisfaction in the ED, and many patients provide high satisfaction ratings after receiving minimal or no pain treatment. Kelly surveyed adult ED users and found that satisfaction was not related to initial or discharge pain score.³⁷ Similarly, Magaret et al.²² surveyed PED parent-child pairs and found that parental report of their child's pain resolution was not significantly associated with satisfaction. The strongest positive association was the quality of provider interactions and information provided; parents who responded affirmatively to the questions, "How pleasant were your interactions with your physician?" and "How adequate was the information provided?" were far more likely to be satisfied.²² Downey and Zun²³ found a similar association when surveying adult ED patients with pain. They reported that satisfaction was most strongly correlated with the following statements: "The doctor told me all I wanted to know about my illness," "The doctor seemed warm and friendly to me," and "This is a doctor I would trust with my life."²³ In our study, most caregivers report being satisfied with their child's pain management despite continued pain upon discharge. There may be other unmeasured or unreported variables that account for this observation, such as a shorter wait time or the communication skills of the nursing staff. Physicians should be careful not to interpret family satisfaction as equivalent to adequate provision of analgesia.

Pain scores at discharge were comparable between the GED and PED, as was the use of non-pharmacologic pain treatments. Further, there was no statistically significant difference in caregiver recall of discharge advice. Still, caregivers reported that the GED clinical team was not prioritizing their children's pain to the same degree as the PED. This would suggest that while treatment of pain might have been comparable between our two sites, the caregiver

perception of prioritization and adequacy of communication of this prioritization was lower for the GED setting. Our study suggests that perhaps some of the previously reported disparity between GED and PED treatment of children's pain^{25,26} may be a result of differences in communication with the caregivers regarding the importance of treating a child's pain.

LIMITATIONS

The convenience sampling method, with its inherent selection bias, small sample size, and exclusion of non-English speakers, are notable limitations of this study. Due to staffing and funding limitations, participants were recruited over a three-year period, which is unusually lengthy for a modest-sized study such as this; of note, this extended recruitment period did allow for representation of all seasons. We asked caregivers about maximum pain in the previous 24 hours, which may not necessarily have been experienced in the ED. As surveys were permitted to be submitted both in person or via mail, it is possible that this dual method of survey return may have led to differential responses between the two types of responders; we did not pursue sub-group analysis based on this factor. Finally, this study only included families who were *treated* for pain in the ED; as such, the experiences of caregivers whose children who had pain but did not receive medication or non-pharmacologic therapies are not represented in this study.

CONCLUSION

Caregivers reported that their children had significant pain before and during an ED visit. Despite this high burden of pain, almost all caregivers were satisfied with their child's ED pain treatment. Caregivers who reported that their children were in severe pain immediately prior to ED discharge were least likely to be satisfied with their children's pain treatment. Of note, over half of caregivers surveyed would not provide an additional dose of medicine if the child's pain persisted. Health care providers should be careful not to misinterpret family satisfaction and hesitance to request more pain medication as equivalent to the provision of adequate analgesia. The complex relationship between satisfaction and pain management needs to be further explored, and barriers to adequate pain treatment addressed. In the future, caregiver reports of satisfaction

could be correlated with child satisfaction reports, as well as medical record reviews.

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SUPPLEMENTARY MATERIAL

To view supplementary material for this article, please visit <http://dx.doi.org/10.1017/cem.2015.68>

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