# **CMAJ Research:**

# A Multicentre Survey of Parental Perspectives and Characteristics Pertaining to Neonatal Visits to Emergency Departments

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# <u>Abstract</u>

**Background:** Parents bring neonates to emergency departments (EDs) for many reasons, often non-urgent. We examined visit characteristics and parental perspectives at Academic Health Science Centres in Ontario, to identify targets for improved efficiencies in the rate of neonatal ED visits.

**Methods:** We developed and implemented a survey that explored: characteristics of neonates and parents evaluated in ED, perspectives of parents, and health-care system use.

**Results:** 1,533 surveys were completed. Most respondents (73.9%) received advice prior to the ED visit. For 86.4%, this was from a health care provider (HCP), who frequently advised going to the ED. While 86.8% of parents reported high confidence in caring for a sick child, 42.3% were unsure of the urgency with 90.5% believing same-day attention was required. Even when parents felt the condition was not serious, 83.2% thought that same-day evaluation was important. Nearly half of respondents (44.4%) said they would have gone to their HCP with a same-day appointment, dropping to 28.1% with a next-day appointment. The most common reasons for presenting were jaundice (28.8%) and feeding issues (16.4%).

**Interpretation:** Reported confidence in caring for sick infants does not match the perceived urgency of neonatal conditions, likely contributing to ED overuse. To decrease non-urgent neonatal ED use, families need better community supports, where HCPs have the resources and confidence to deal with this vulnerable population. This system would need to be immediately responsive, providing same-day help. Education campaigns for families should be explored for common presenting complaints, such as gastrointestinal, jaundice and feeding concerns.

# **Introduction**

As emergency department (ED) visits continue to increase, health-care systems require strategies to deal with non-urgent ED use in more effective ways while refocusing limited resources on higher acuity patients. This becomes particularly complicated for infants and young children, who depend on parents to determine if urgent medical attention is required. Indeed, up to 41% of children are brought to EDs in their first year,<sup>1-7</sup> with 25-50% visiting more than once<sup>2,3,5</sup> and 49-70% presenting with non-urgent concerns.<sup>5,8,9</sup> Much less is known about neonatal visits, those within 28 days of birth, although a nationally representative study in the United States estimated that 7.6% of newborns had an ED visit within this period.<sup>10</sup> In Ontario, that could mean that of the approximately 140,000 annual births,<sup>11</sup> about 10,640 neonates may visit an ED each year, with up to 7,448 (70%) of them non-urgent.

Neonatal ED visits are often related to parental concerns inadequately addressed in the transition from hospital to home, and may occur prior to the first scheduled appointment with the primary care provider. We wanted to learn what drives these visits and if there are better alternatives. We developed and conducted a quantitative survey to explore the characteristics of newborns and their parents who attend the ED within 28 days of delivery. The survey was also designed to explore the parental perspectives on their experiences with the health care system prior to the ED visit. We believe this to be the largest multi-centre study of neonatal ED visits to date.

# **Methods**

# Participants

Parents or guardians presenting with a neonate to the ED at one of five Ontario Academic Health Science Centres (AHSC) associated with the Pediatric Emergency Research Canada (PERC) Network were eligible for the survey. Families of neonates requiring resuscitation and those unable to read English or French sufficiently well to complete the survey were excluded. Surveys were distributed between December 2013 and June 2015, with all sites participating for a minimum of 6 months.

We used a convenience sampling approach with survey distribution strategies varying by site based on local ED work flow. We anticipated approximately 5,000 ED visits to the five AHSCs in a one-year period, and targeted a sample size of 1,500 completed surveys. Surveys were completed anonymously, collected locally and returned in batches to the coordinating site. Data were entered centrally into a secure research database (REDCap)<sup>12</sup> by a research assistant.

# Survey tool development

Since no validated survey instrument exists for this patient population and setting, a survey was developed by researchers at the coordinating site. A widely used framework for analyzing factors associated with health care service utilization,<sup>13</sup> existing literature on reasons for and predictors of ED use in pediatrics and the expertise of the research team were used to develop the survey. We mapped each survey item to one of the following domains: environment (health care system and external environment), population (predisposing, enabling and need) and health

behaviour (personal health choices and use of health services). Face validity of the survey was established by expert reviewers in Pediatric Emergency Medicine and it was piloted at the coordinating site for usability, acceptability and user input. The survey was adjusted according to the pilot results and the final version was translated into French.

## **Ethics**

Each participating site obtained Research Ethics Board approval for the study. All participant responses remained confidential and only aggregate data are reported. In all centres, eligible parents received a survey along with a cover letter explaining voluntary participation in the study and that returning the completed study implied consent.

## Analysis

All data analyses were performed using the R language version 3.3.1.<sup>14</sup> The primary analysis entailed a descriptive summary of characteristics of neonates and parents visiting the ED, using frequencies and percentages. Demographic characteristics of eligible and surveyed ED visits were assessed and compared using Pearson's chi-squared test or Fisher's exact test as appropriate. Two-sided p-values less than 0.05 were considered statistically significant. Exploratory secondary data analysis was done to examine potential correlations of variables after reviewing the results of the primary analysis.

# **Results**

A total of 1,533 completed surveys were received from 8,610 potentially eligible ED visits. Table 1 compares the surveyed population to the eligible population; the surveyed population is slightly under-represented for weekend visits and visits between midnight and 0800, but did not differ from the eligible population for age at presentation or infant sex.

# **Participants**

Most babies were born full term, never separated from their mother and discharged within 48hours of birth. Table 2 summarizes the characteristics of the birth and hospital stay. In describing their infant, 88.8% of parents agreed with the statement that their infant was "as healthy as other children", while 15.8% agreed their infant was "more fragile than others", 8.5% agreed that their infant "gets sick more easily than others" and 6.3% agreed their infant "has a long-term condition".

The majority of participants were married, had college or university education and a family annual income of \$50,000 or more (Table 3).

## Health care system contact

Among parents who reported being asked in the birth hospital whether they had a health care provider (HCP) for their baby, 80.2% said they were also asked whether they had an appointment scheduled after discharge. This indicates a missed opportunity in nearly 20% of cases to reinforce the importance of early post-discharge follow-up. On the survey, nearly all

families (90.6%) indicated having an HCP, which includes family doctors, pediatricians, midwives, nurse practitioners and others. The majority (76.7%) had had an appointment with their HCP between discharge from the birth hospitalization and this ED visit. Of respondents with an HCP, 35.9% reported that they could contact the office outside of regular hours.

In 8.8% of cases, parents reported having brought the baby to the ED previously and 61.2% of these repeat visits occurred for the same concern. The majority of repeat visits (74.1%) were within 7 days and 40.5% were within 2 days of the index ED visit. Recurrent visits due to the same problem occurred earlier compared to those due to a different problem (p=0.01).

## Clinical issues

Just over half the parents (51.7%) identified a single presenting problem, 22.6% identified two problems and 20.5% reported more than two issues. Table 4 outlines the reasons for the visit. Parents were allowed to choose as many issues as applicable and responses are grouped for clarity in the table. Jaundice, feeding, elimination problems, respiratory issues, fever and crying were the most commonly reported concerns.

## Pre-ED visit advice and family management

Most respondents (73.9%) had received advice from someone before coming to the ED. In 86.4% of cases, this advice came from a health care provider. A total of 46.7% of parents with a usual HCP contacted their HCP before coming to the ED and 67.5% of these parents were advised to bring the baby to ED.

The most commonly reported reasons for not contacting their usual HCP included: unable to reach them, received advice to come to ED, believed the problem was more appropriate for the ED or might require tests in ED, or felt their HCP would refer them to ED anyway. Only 18.1% of families reported attempting a treatment at home (e.g., feeding, comfort measures, acetaminophen) before presenting to the ED.

## Perceptions of severity and urgency

The majority of respondents (86.8%) reported being quite or very confident to take care of a sick or injured child. This rate was higher in respondents with another child in the home versus those without (93.5% vs. 79.1%, p<0.001).

Despite this, 42.3% of parents were not certain of the severity of their infant's condition and 90.5% of these parents felt that the infant required assessment immediately/same-day; 18.1% reported that something bad may happen if the baby was not seen within 24 hours.

Even among the 16% of respondents who described their infant's condition as not very serious, 83.2% still felt that same-day assessment was required and 14.9% perceived that something bad might happen if not seen within 24 hours. See Tables 5 and 6 for details of these relationships.

About half of the parents (50.8%) expected that their infant would be seen in ED within one hour.

#### Exposure to information about babies

Over 90% of respondents reported having received information on common infant health topics, often from multiple sources (see Table 7) and 20.5% said they'd received conflicting or confusing advice. Parents who brought their child to ED with jaundice were slightly more likely to report having received advice about jaundice compared to parents who brought their child to ED for other reasons (96.4% vs. 91.3%, p<0.001).

#### Redirection to other health care resources

We explored what additional resources were perceived as potentially useful in their decision to bring their baby to the ED, and found parents rated somewhat or very helpful:

- Walk-in clinics with pediatric specialists 74.2%.
- 24 hour telephone advice from pediatric nurses or doctors 73.5%.
- Easier access to baby's doctor 72.5%.
- Postnatal home visits from nurses or doctors 70.6%.
- Reading material provided during the birth admission 64.7%.
- Information on the Internet 58.8%.
- Information in newspapers/magazines or on TV/radio 34.8%.

When asked whether an appointment with an HCP would have prevented the ED visit, 44.4% of parents said yes for a same-day appointment but only 28.1% if the appointment was within 24 hours.

## **Interpretation**

#### Summary

Our study provides a broad understanding of why parents bring their infants to the ED, highlighting that both parents and HCPs see neonates as in need of expedient, often same-day, care and that unilateral interventions are unlikely to be successful. The majority of parents reach out to HCPs before making a decision to come to the ED, suggesting an opportunity to direct them to other available resources. Our results also demonstrate that while parents have an opinion as to the severity of their infant's condition, they are uncertain — likely a major contributor to the decision to seek care in the ED rather than other health care settings. This is reinforced by our finding that nearly half of respondents said they would have gone to their HCP if they could be seen the same day but this dropped to just over a quarter of respondents if the appointment would be the next day.

Previous studies in pediatrics have found high rates of children having an identified primary care provider<sup>15,16</sup> and our study confirmed this for the neonatal population. We found that low acuity presentations of gastrointestinal issues, including jaundice and problems with feeding or stooling, continue to be the most frequent causes for ED visits, along with respiratory concerns,

crying and rash.<sup>10,17-19</sup> Also consistent with the literature,<sup>15,16,20,21</sup> repeated visits to the ED, often for the same issue, were frequent in our study despite the majority of respondents having an HCP for their baby. This may suggest that the ED consultation does not always provide complete reassurance or support for parental concerns.

The large majority of parents had seen their HCP between initial hospital discharge and the ED visit, suggesting that an early appointment did not prevent an ED consultation. This may be in part due to the fact that while most parents reported a high confidence level for taking care of a sick or injured child, a large proportion were unsure of the severity of their infant's condition and believed that it was sufficiently urgent to warrant being seen the same day. Even in cases where parents thought that their infant's condition was not serious, it was common to think that being seen the same day was important. This is consistent with the findings of others indicating that parents, including those of infants triaged as non-urgent, have difficulty discerning the urgency of the situation and frequently report it as very/extremely urgent.<sup>21,22</sup> What's more, even if the majority of parents sought advice prior to coming to ED, HCPs generally advised that the baby be seen in the ED, a trend that is well documented.<sup>15,16,20,21,23</sup>

Parent confidence and knowledge as well as HCP direction to parents to attend the ED are both key to consider when designing interventions to decrease non-urgent neonatal ED visits. Education is often used to modify health behaviours and there is evidence that education can affect ED presentation rates in this population. For example, a provincial public health prevention program focused on crying led to a decreased rate of ED presentation in infants under 5 months of age.<sup>24</sup> However, education alone may not be sufficient. Our finding that those presenting with jaundice were more likely to have received information on hyperbilirubinemia as compared to others may indicate that families were sensitized to the issue but not well informed as to where to seek care.

Parents in our study had generally received information on a broad range of topics and our results show that they rated human-based resources, including more ready access to physicians or nurses, as potentially more helpful than further information-based resources, regardless of format. This speaks to the potential positive impact of HCPs in the care of infants. Interventions to improve the capacity of HCPs to address non-urgent neonatal concerns when parents call should be considered. These HCPs need the skills and confidence to address the issues as well as access to resources which might be required, such as community labs capable of performing infant bloodwork with quick turnaround or lactation consultants etc.

Further studies are needed to determine which of the common presenting issues - such as jaundice, feeding, respiratory issues, crying and rash – may be amenable to education campaigns for families versus which will be more effectively dealt with through interventions aimed at HCPs or improving community resources.

## Limitations

Conducting the survey in large AHSCs may affect generalizability to more rural settings. While we know the number of completed surveys and the number of potentially eligible neonates, we

do not know the number of surveys distributed and cannot calculate a true response rate. Visits were counted as potentially eligible based on patient age and presenting during the study period but may not have met full eligibility criteria (e.g., language, not requiring resuscitation). There may be selection bias in those who chose to complete the survey and patients requiring resuscitation were excluded which may have decreased our numbers of more severe presentations. Comments by ED staff may have affected parents' interpretations of the seriousness of the illness compared to their decision to come to the ED. All data is self-reported and cannot be correlated to final diagnosis or HCP assessed severity.

#### Conclusion

Capitalizing on parents' reported confidence by providing families better supports to care for their baby at home or be seen outside the ED may decrease non-urgent ED utilization by neonates. Any such system would need to be immediately responsive, providing same-day support, to have the desired effect. Targeted interventions to decrease ED visits for gastrointestinal complaints may have a significant effect on utilization, as these were by far most common, as would community resource to ensure timely assessment for jaundice and support of feeding issues.

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#### Table 1: Comparison of potentially eligible and included patient characteristics

					Surveyed vs
	Eligible	0/	Surveyed	0/	eligible
Characteristics	N	%	N	%	p-value
Total	8610	-	1533	-	-
Sex					0.53
Воу	4801	55.8	836	54.9	
Girl	3809	44.2	688	45.1	
Total	8610	100	1533	100	
Age group (days)					0.36
0-3	1089	12.7	202	13.2	
4-7	1958	22.8	371	24.2	
8-14	1996	23.2	367	23.9	
15-21	1786	20.8	305	19.9	
22-28	1774	20.6	288	18.8	
Total	8603	100.1	1533	100	
Day of Week					0.01
Sunday	1210	14.1	163	10.8	
Monday	1264	14.7	245	16.2	
Tuesday	1160	13.5	230	15.2	
Wednesday	1199	13.9	218	14.4	
Thursday	1135	13.2	216	14.3	
Friday	1346	15.6	229	15.1	
Saturday	1296	15.1	211	14	
Total	8610	100.1	1512	100	
Visit Time					<0.001
8:00 am - 4:59 pm	3965	46.1	767	50.9	
5:00 pm - 11:59 pm	3387	39.3	653	43.3	
Midnight - 7:59 am	1258	14.6	87	5.8	
Total	8610	100	1507	100	
Site					<0.001
A	2303	26.7	947	61.8	
В	1428	16.6	185	12.1	
С	309	3.6	32	2.1	
D	178	2.1	33	2.2	
E	4392	51	336	21.9	
Total	8610	100	1533	100.1	

\*age of 7 patients was suppressed by one site due to small numbers

## Table 2: Characteristics of pregnancy / infant / initial hospital stay

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ot applicable/born at home	333	22.
	72	5
	46	3.2
For Peer Review Only		

#### Table 3: Characteristics of parents/guardians

Family status (n=1442)	Ν	%
Married/living with partner	1328	92.1
Separated/divorced, partner involved with child	23	1.6
Single parent	91	6.3

#### Age Distribution - Respondent (n=1439)

< 20 years	38	2.6
20-24 years	151	10.5
25-29 years	391	27.2
30-34 years	499	34.7
35-39 years	267	18.6
40 years or older	93	6.5

#### Age Distribution - Partner (n=1507)

N/A	20	1.4
< 20 years	22	1.6
20-24 years	99	7
25-29 years	296	21
30-34 years	469	33.3
35-39 years	349	24.8
40 years or older	152	10.8

#### Other children living at home (n=1449)

No	661	45.6
Yes	788	54.4

#### Employment Status - Respondent (n=1396)

30-34 years	469	33.3	
35-39 years	349	24.8	
40 years or older	152	10.8	
Other children living at home (n=1449)			
No	661	45.6	
Yes	788	54.4	
Employment Status - Respondent (n=1396)			
· · · · · · · · · · · · · · · · · · ·			
Caring for home/family	162	11.6	
On parental leave	723	51.8	
Working	249	17.8	
•			
Other	262	18.8	

#### Employment status - Partner (n=1533)

Caring for home/family	64	4.7
On parental leave	305	22.5
Working	816	60.1
Other	172	12.7

#### Highest level of education - Respondent (n=1500)

High school	216	15.4
Vocational school/trade certificate or apprenticeship	35	2.5
Some college/university	171	12.2
College diploma	296	21.1

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Undergraduate degree	324	23.1
Graduate degree	237	16.9
Professional degree	121	8.6

#### Highest level of education - Partner (n=1449)

N/A	35	2.6
High school	213	15.8
Vocational school/trade certificate or apprenticeship	69	5.1
Some college/university	121	9
College diploma	309	22.9
Undergraduate degree	268	19.9
Graduate degree	215	15.9
Professional degree	119	8.8

#### Combined income (n=1419)

< \$25,000/year	128	9
\$25,000 - \$50,000/year	193	13.6
\$50,000 - \$100,000/year	394	27.8
>\$100,000/year	448	31.6
Prefer not to say	256	18

#### Province of Residence (n=1037)

Province of Residence (n=1037)	
Ontario Quebec Other	889 85.7 132 12.7 16 1.5

# Table 4: ED presenting issue(s) reported by parent/guardian

Diagnosis	Multi-select N (%)	Number of respondents who selected at least one item in this category (%)
Gastrointestinal		926 (60.4)
Jaundice / yellow colour of skin or eyes	441 (47.6)	
Feeding problem	251 (27.1)	
Vomiting	201 (21.7)	
Problem with stool	179 (19.3)	
Diarrhea	109 (11.8)	
Ate something s/he shouldn't have	1 (0.1)	
Respiratory		403 (26.3)
Congestion	249 (61.8)	
Trouble breathing	222 (55.1)	
Cough	190 (47.1)	
Choked	31 (7.7)	
Apnea / ALTE	6 (1.5)	
Neurological		16 (1.0)
Shaking / tremor / seizure	16 (100.0)	-
Trauma		70 (4.6)
Lump / bump / swelling / abscess	38 (54.3)	
Fall	14 (20.0)	
Possible broken bone	12 (17.1)	
MVA / other accident	5 (7.1)	
Cut / scrape / bruise	2 (2.9)	
Cardiac		14 (0.9)
Murmur / other cardiac	14 (100.0)	
Behaviour		206 (13.4)
Crying	135 (65.5)	
Sleeping problem	99 (48.1)	
Lethargy / difficult to wake / acting different	19 (9.2)	
Skin/dermatologic	,	194 (12.7)
Rash	82 (42.3)	
Problem with eyes / eye discharge	80 (41.2)	
Redness / discharge near cord stump	36 (18.6)	
Allergic reaction	7 (3.6)	
Skin or nail colour	4 (2.1)	
Infectious	. (=)	150 (9.8)
Fever	138 (92.0)	
Thrush	8 (5.3)	
Infection	4 (2.7)	
Urinary	· ( <u>-</u> ., )	106 (6.9)
Problem with urine	85 (80.2)	
Circumcision	24 (22.6)	
Other	_ ()	16 (1.0)
Check up	4 (25.0)	
Vaginal secretions / bleeding	4 (25.0)	
Syndrome / anomaly	4 (25.0)	
Problems with ear	4 (25.0) 3 (18.8)	
Doctor referral	3 (10.0) 1 (6.2)	
	1 (0.2)	39 (2.5)

## Table 5: Seriousness of problem versus urgency to be seen

Perceived illness severity

	reiceiveu illiess severity			
Urgency to be seen	Not very serious	Serious	Very serious	Not sure
	n %	n %	n %	n %
Immediately	73 30.7	219 45.8	117 78.5	241 37.7
Today	125 52.5	227 47.5	28 18.8	337 52.7
Within a few days	40 16.8	32 6.7	4 2.7	61 9.5

# Table 6: Seriousness of problem versus probability of something bad happening in next 24 hours

	Ferceived inness sevenity							
Will something bad happen if not seen < 24h	Not v serio		Seri	ous		/ery rious	Not s	ure
	n	%	n	%		n %	n	%
Definitely not	33	13.6	9	1.9		1 0.7	17	2.7
Probably not	110	45.5	100	21.1	1	3 8.8	125	19.9
Probably	29	12	155	32.6	4	3 29.3	96	15.3
Definitely	7	2.9	59	12.4	4	1 27.9	18	2.9
Don't know	63	26	152	32	4	9 33.3	373	59.3

#### Perceived illness severity

#### Table 7: Advice/information received by parent/guardian and timing/source

Торіс	Number of respondents who Multi- selected at least on select item in this categor N (%) (%)
How much to feed my baby	1439 (93.9)
At a class before birth	329 (22.9)
In hospital after birth	958 (66.6)
From my midwife	158 (11.0)
From my baby's usual doctor	311 (21.6)
Previous pregnancy	473 (32.9)
No advice	76 (5.3)
How often to feed my baby	1434 (93.5)
At a class before birth	319 (22.2)
In hospital after birth	993 (69.2)
From my midwife	161 (11.2)
From my baby's usual doctor	303 (21.1)
Previous pregnancy	473 (33.0)
No advice	47 (3.3)

How many wet (urine) diapers to expect per day		1421 (92.7
At a class before birth	320 (22.5)	
In hospital after birth	944 (66.4)	
From my midwife	161 (11.3)	
From my baby's usual doctor	274 (19.3)	
Previous pregnancy	426 (30.0)	
No advice	82 (5.8)	
How many dirty (stool) diapers to expect per day		1424 (92.9
At a class before birth	312 (21.9)	
In hospital after birth	943 (66.2)	
From my midwife	166 (11.7)	
From my baby's usual doctor	279 (19.6)	
Previous pregnancy	428 (30.1)	
No advice	82 (5.8)	
Jaundice (yellow skin colouration)		1422 (92.8
At a class before birth	220 (15.5)	
In hospital after birth	947 (66.6)	
From my midwife	141 (9.9)	
From my baby's usual doctor	287 (20.2)	
Previous pregnancy	364 (25.6)	
No advice	108 (7.6)	
Crying and how to comfort my baby		1400 (91.3
At a class before birth	299 (21.4)	
In hospital after birth	613 (43.8)	
From my midwife	115 (8.2)	
From my baby's usual doctor	149 (10.6)	
Previous pregnancy	485 (34.6)	
No advice	243 (17.4)	
When to see a doctor for well-baby check		1391 (90.7
At a class before birth	196 (14.0)	
In hospital after birth	868 (62.0)	
From my midwife	121 (8.6)	
From my baby's usual doctor	314 (22.4)	
Previous pregnancy	369 (26.4)	
No advice	81 (5.8)	