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Parental characteristics and perspectives pertaining to neonatal visits to the emergency department: a multicentre survey

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Parental characteristics and perspectives pertaining to neonatal visits to the emergency department: a multicentre survey

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Abstract

Background: Parents take neonates to the emergency department for many reasons, often nonurgent, pressuring an already burdened system. We aimed to characterize these visits and families to identify potential strategies to decrease neonatal emergency department visits.

Methods: We developed and implemented a survey that explored characteristics of neonates and parents/guardians evaluated in the emergency department, perspectives of parents and use of health care services. Parents presenting with a neonate to the emergency department in 5 large academic hospitals in Ontario were surveyed between December 2013 and June 2015. We used descriptive statistics to report survey data and explored correlations between factors.

Results: A total of 1533 surveys were completed. The most common reasons for presenting were jaundice (441 [28.8%]) and feeding issues (251 [16.4%]). The majority of respondents (73.9% [1104/1494]) had received advice before going to the emergency department. In most cases (86.4% [954/1104]), this was from a health care provider, who frequently advised going to the emergency department. Although most parents (86.8% [1280/1475]) reported high confidence in caring for a sick or injured child, 42.3% (643/1519) were unsure of the severity, and most (90.4% [578/639]) of these parents felt that the infant required assessment immediately or the same day. Of parents who felt the condition was not serious, 83.2% (198/238) thought that same-day evaluation was required. Nearly half of respondents (44.4% [621/1400]) said they would have gone to their health care provider with a same-day appointment, and 28.1% (344/1225) would have gone to their care provider with a next-day appointment.

Interpretation: Parents' reported confidence in caring for sick or injured infants does not match the perceived urgency of neonatal conditions, which likely contributes to emergency department overuse. Any system to decrease nonurgent emergency department use by neonates would need to be immediately responsive, providing same-day help.

As emergency department visits increase, health care systems require strategies to deal with nonurgent emergency department use in more effective ways while refocusing limited resources on higher-acuity cases. This becomes particularly complicated in the case of infants and young children, who depend on parents to determine whether urgent medical attention is required. Indeed, up to 41% of children are brought to emergency departments in their first year,¹⁻⁷ with 25%–50% visiting more than once^{2,3,5} and 49%–70% presenting with nonurgent concerns.^{5,8,9} Much less is known about neonatal visits (within 28 d of birth), although Lee and colleagues,¹⁰ in a nationally representative study in the United States, estimated that 7.6% of newborns had an emergency department visit within this period. In Ontario, that could mean that, of the roughly

140 000 annual births,¹¹ about 10 640 neonates may visit an emergency department each year, with up to 7448 visits (70.0%) being nonurgent.

In Ontario, most babies are born in hospital and are subsequently followed in the community by a family physician, pediatrician or midwife within a few days. Ante-/postnatal education is not standardized across institutions or practitioners.

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Neonatal emergency department visits are often related to parental concerns inadequately addressed in the transition from hospital to home and may occur before the first scheduled appointment with the primary care provider. We wanted to learn what drives these visits and whether there are better alternatives to an emergency department visit. We conducted a quantitative survey to explore the characteristics of newborns and their parents who attend the emergency department within 28 days of birth. The survey was also designed to explore parents' perspectives on their experiences with the health care system before the emergency department visit.

Methods

Setting and participants

Parents or guardians presenting with a neonate to the emergency department at 1 of 5 Ontario academic health science centres (Children's Hospital of Eastern Ontario, Ottawa, Hotel Dieu Hospital, Kingston, London Health Sciences Centre, McMaster Health Sciences Centre, Hamilton, or The Hospital for Sick Children, Toronto) were eligible for the survey. Parents of neonates requiring resuscitation were excluded as it was not thought to be appropriate to approach them while their baby was unstable. Also excluded were parents who were unable to read English or French sufficiently to complete the survey. 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 emergency department work flow. We expected about 5000 emergency department visits to the 5 hospitals in a 1-year period and targeted a sample size of 1500 completed surveys. In all centres, hospital staff or research volunteers gave eligible parents a survey along with a cover letter explaining that participation in the study was voluntary and that returning the completed survey implied consent to participate. Surveys were completed anonymously in the hospital at the time of the emergency department visit, collected locally and returned in batches to the coordinating site. No incentives were provided for survey completion.

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 (J.H., M.L., K.A.M., R.L.Z.). We employed a widely used framework for analyzing factors associated with use of health care services,¹² existing literature on reasons for and predictors of emergency department use in pediatrics, and the expertise of the research team to develop the survey. We mapped each survey item to 1 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 care services). We then assessed for duplication among items and reduced their number to balance the domains, decrease redundancy and ensure a manageable final number of items.

Face validity of the survey was established by expert reviewers in pediatric emergency medicine, including K.A.M. and R.L.Z. The survey was piloted for usability, acceptability and user input with 60 families at the coordinating site. It was adjusted according to the pilot results, and the final version was translated into French. The survey can be found in Appendix 1 (available at www.cmajopen.ca/content/6/3/E423/suppl/DC1).

Statistical analysis

The data were entered centrally into a secure research database (REDCap¹³) by a research assistant. Partially completed surveys were included, and proportions were calculated relative to the number of respondents who answered each question. The primary analysis entailed a descriptive summary of characteristics of neonates and parents visiting the emergency department, with the use of frequencies and percentages. We assessed and compared demographic characteristics of eligible and surveyed emergency department visits using the Pearson χ^2 test or the Fisher exact test, as appropriate. Two-sided p values < 0.05 were considered statistically significant. We performed exploratory secondary data analysis to examine potential correlations of variables after reviewing the results of the primary analysis. We conducted all data analyses using the R language version 3.3.1 (R Foundation for Statistical Computing, <https://www.R-project.org/>).

Ethics approval

Each participating site obtained research ethics board approval for the study. All participant responses remained confidential, and only aggregate data are reported.

Results

A total of 1533 surveys were received from 8610 potentially eligible emergency department visits. Rates were calculated based on the number of respondents to each question, and therefore the denominator changes frequently and is shown for transparency.

A comparison of the surveyed population and the eligible population is presented in Table 1. The surveyed population was slightly underrepresented for weekend visits and visits between 0000 and 0800 but did not differ from the eligible population for age at presentation or infant sex.

Most babies were born at term, were never separated from their mother and were discharged within 48 hours of birth. Table 2 summarizes the characteristics of the birth and the hospital stay. In describing their infant, 88.8% of parents/guardians (1295/1459) agreed that their infant was as healthy as other babies, 15.8% (226/1426) agreed that their infant was more fragile than other babies, 8.5% (119/1393) agreed that their infant got sick more easily than other babies, and 6.3% (87/1386) agreed that their infant had a long-term health condition. The majority of participants were married, had college or university education, and had a family annual income of \$50 000 or more (Appendix 2, available at www.cmajopen.ca/content/6/3/E423/suppl/DC1).

Table 1: Characteristics of potentially eligible and included patients/visits to the emergency department

Characteristic	No. (%) of patients		p value
	Eligible n = 8610	Surveyed n = 1533	
Sex			0.5
Male	4801 (55.8)	836 (54.8)	
Female	3809 (44.2)	688 (45.1)	
Missing	0	9	
Age group, d			0.4
≤ 3	1089 (12.6)	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)	
Missing	7	0	
Day of week			0.01
Sunday	1210 (14.0)	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 (15.0)	211 (14.0)	
Missing	0	21	
Visit time			< 0.001
0800–1659	3965 (46.0)	767 (50.9)	
1700–2359	3387 (39.3)	653 (43.3)	
0000–0759	1258 (14.6)	87 (5.8)	
Missing	0	26	
Site			< 0.001
A	2303 (26.7)	947 (61.8)	
B	1428 (16.6)	185 (12.1)	
C	309 (3.6)	32 (2.1)	
D	178 (2.1)	33 (2.2)	
E	4392 (51.0)	336 (21.9)	

Contact with health care system

Of the 87.8% of parents (1276/1454) who reported being asked in the birth hospital whether they had a health care provider (e.g., family doctor, pediatrician, midwife, nurse practitioner) for their baby, 80.2% (1005/1253) said they were also asked whether they had an appointment scheduled after discharge. On the survey, most parents (90.6% [1356/1496]) indicated having a health care provider. The majority (76.7% [1029/1342]) had had an appointment with their health care provider between discharge from the birth hospital and the emergency department visit. Finally, 35.9% of parents

Table 2: Characteristics of delivery/infant/hospital stay

Characteristic	No. (%)
Type of delivery (n = 1459)	
Cesarean	335 (23.0)
Vaginal	1124 (77.0)
Gestational age (n = 1467)	
< 35 wk	19 (1.3)
35 wk to 37 wk and 6 d	227 (15.5)
38 wk to 41 wk and 6 d	1202 (81.9)
≥ 42 wk	19 (1.3)
Separation of mother and baby (n = 1447)	
No, always with mother	1270 (87.8)
Yes, baby was sick/small	157 (10.8)
Yes, mother was sick	20 (1.4)
Length of stay, h (n = 1453)	
< 24	145 (10.0)
24–36	510 (35.1)
37–48	347 (23.9)
49–96	333 (22.9)
> 96	72 (5.0)
Not applicable/born at home	46 (3.2)

(470/1309) with a health care provider reported that they could contact the office outside of regular hours.

In 8.8% of cases (133/1513), parents reported having taken the baby to the emergency department previously, and 61.2% (79/129) of these repeat visits occurred for the same concern. The majority of repeat visits (74.1% [86/116]) were within 7 days of the index emergency department visit; 40.5% (47/116) were within 2 days. Recurrent visits due to the same problem occurred sooner than those due to a different problem ($p = 0.01$).

Clinical issues

Just over half of parents (54.5% [792/1453]) identified a single presenting problem, 23.8% (346/1453) identified 2 problems, and 21.7% (315/1453) reported more than 2 problems. Table 3 outlines the reasons for the visit. Jaundice, feeding issues, elimination problems, respiratory issues, fever and crying were the most commonly reported concerns.

Advice and family management before emergency department visit

The majority of parents (73.9% [1104/1494]) had received advice from someone before going to the emergency department. In most cases (86.4% [954/1104]), this advice came from a health care provider. Almost half of parents (46.7% [622/1332]) with a usual health care provider contacted their care provider before going to the emergency department, and 67.5% of these parents (420/622) were advised to take the baby to the emergency department.

Table 3: Presenting issue(s) reported by parent/guardian

Issue	No. (%) of respondents*
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 she/he should not 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/apparent life-threatening event	6 (1.5)
Neurological: shaking/tremor/seizure	16 (1.0)
Trauma	70 (4.6)
Lump/bump/swelling/abscess	38 (54.3)
Fall	14 (20.0)
Possible broken bone	12 (17.1)
Motor vehicle crash/other accident	5 (7.1)
Cut/scrape/bruise	2 (2.8)
Cardiac: murmur/other	14 (0.9)
Behavioural	206 (13.4)
Crying	135 (65.5)
Sleep problem	99 (48.0)
Lethargy/difficult to waken/acting "different"	19 (9.2)
Skin/dermatologic	194 (12.6)
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	106 (6.9)
Problem with urine	85 (80.2)
Circumcision	24 (22.6)
Other	16 (1.0)
Examination	4 (25.0)
Vaginal secretion/bleeding	4 (25.0)
Syndrome/anomaly	4 (25.0)
Problem with ear	3 (18.8)
Doctor referral	1 (6.2)
Do not know	39 (2.5)

*Respondents could choose as many issues as applicable within each category.

The most commonly reported reasons for not contacting the usual health care provider included being unable to reach the care provider, receiving advice to go to the emergency department, believing the problem was more appropriate for or might require tests in the emergency department, or feeling that the care provider would refer the baby to emergency department anyway. Some parents (18.1% [268/1477]) attempted treatment (e.g., feeding, comfort measures, acetaminophen administration) at home before presenting to the emergency department.

Perceptions of severity and urgency

Most parents (86.8% [1280/1475]) reported being quite or very confident to take care of a sick or injured child. This rate was higher among respondents with another child in the home than among those without (93.5% v. 79.1%) ($p < 0.001$).

A total of 42.3% of parents [643/1519] were not certain of the severity of their infant's condition, and most (90.4% [578/639]) of these parents felt that the infant required assessment immediately or the same day; 18.1% (114/629) believed that something bad might happen if the baby was not seen within 24 hours. Of the 16.0% of parents (243/1519) who described their infant's condition as not very serious, 83.2% (198/238) felt that same-day assessment was required, and 14.9% (36/242) believed that something bad might happen if the baby was not seen within 24 hours (Table 4).

About half of parents (50.8% [764/1504]) expected that their infant would be seen in the emergency department within 1 hour.

Exposure to information about babies

Most parents reported having received information on common infant health topics, often from multiple sources (Table 5); 22.1% (315/1424) said they had received conflicting or confusing advice. Parents who took their child to the emergency department with jaundice were more likely to report having received advice about jaundice than those who took their child to the emergency department for other reasons (96.4% v. 91.3%) ($p < 0.001$).

Redirection to other health care resources

Parents rated the following resources somewhat or very helpful in deciding whether to take their baby to the emergency department: walk-in clinic with pediatric specialist (74.2% [973/1311]), 24-hour telephone advice from pediatric nurse or doctor (73.5% [984/1338]), easier access to baby's doctor (72.5% [948/1307]), postnatal home visit by nurse or doctor (70.6% [918/1301]), reading material provided during the birth hospital stay (64.7% [861/1330]), information on the Internet (58.8% [777/1322]), and information in newspapers/magazines or on television/radio (34.8% [458/1316]). When asked whether an appointment with a health care provider would have prevented the emergency department visit, 44.4% of parents (621/1400) said yes for a same-day appointment, and 28.1% (344/1225) said yes if the appointment was within 24 hours.

Table 4: Parent/guardian perception of illness severity in terms of urgency and expected outcome

Urgency/outcome	Perceived illness severity; no. (%) of respondents			
	Not very serious	Serious	Very serious	Not sure
Urgency to be seen	<i>n</i> = 238	<i>n</i> = 478	<i>n</i> = 149	<i>n</i> = 639
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)
Will something bad happen if not seen within 24 h?	<i>n</i> = 242	<i>n</i> = 475	<i>n</i> = 147	<i>n</i> = 629
Definitely not	33 (13.6)	9 (1.9)	1 (0.7)	17 (2.7)
Probably not	110 (45.4)	100 (21.0)	13 (8.8)	125 (19.9)
Probably	29 (12.0)	155 (32.6)	43 (29.2)	96 (15.3)
Definitely	7 (2.9)	59 (12.4)	41 (27.9)	18 (2.9)
Do not know	63 (26.0)	152 (32.0)	49 (33.3)	373 (59.3)

Interpretation

Our results provide a perspective on why parents take their infant to the emergency department, highlighting that both parents and health care providers see neonates as in need of expedient, often same-day, care and that unilateral interventions are unlikely to be successful. The finding that a majority of parents reached out to health care providers before making a decision to go to the emergency department suggests an opportunity to direct parents to other available resources. Our results also show that, although parents have an opinion as to the severity of their infant's condition, they are uncertain. This is likely a major contributor to the decision to seek care in the emergency department rather than in another health care setting. This is reinforced by our finding that nearly half of respondents said they would have gone to their health care provider if they could have been seen the same day, whereas if the appointment were the next day, just over a quarter of respondents would have gone to their health care provider.

Previous studies showed that a high proportion of children have an identified primary care provider,^{14,15} and our findings confirm this for the neonatal population. In the current study, failure to ask whether the family had an appointment with their health care provider before discharge from the birth hospital was a missed opportunity to reinforce the importance of early postdischarge follow-up in nearly 20% of cases. Like other investigators,^{10,16–18} we found that low-acuity presentations of gastrointestinal issues, including jaundice and problems with feeding or stooling, were the most frequent causes for emergency department visits, along with respiratory concerns, crying and rash. Also consistent with the pediatric literature,^{14,15,19,20} repeated visits to the emergency department, often for the same issue, were frequent, even though most respondents reported having a health care

provider for their baby. This suggests that the emergency department consultation may not always provide complete reassurance or support for parental concerns. The fact that most parents had seen their health care provider between discharge from the birth hospital and the emergency department visit indicates that an early appointment did not prevent presentation to the emergency department. This may be in part due to the fact that, although most parents reported a high level of confidence 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 in which parents thought that their infant's condition was not serious, many thought that being seen the same day was important. This is consistent with previous studies indicating that parents, including those of children whose condition is triaged as nonurgent, have difficulty discerning the urgency of the situation and frequently report it as very/extremely urgent.^{20,21} Furthermore, even though the majority of parents sought advice before going to the emergency department, health care providers generally advised that the baby be seen in the emergency department, a trend that is well documented in older pediatric patients.^{14,15,19,20,22}

Education is often used to modify health behaviours, and there is evidence that education can affect rates of presentation to the emergency department in the infant population. For example, a provincial public health prevention program focused on crying led to a decreased rate of emergency department presentation among infants less than 5 months of age.²³ However, education alone may not be sufficient. Our finding that parents of babies presenting with jaundice were more likely than other parents to have received information on hyperbilirubinemia may indicate that families were sensitized to the issue but were not well informed as to where to seek care. Parents in our study had generally received

Table 5: Advice/information received by parent/guardian and timing/source of advice

Topic; source	No. (%) of respondents*
How much to feed baby	1439 (93.9)
At a class before birth	329 (22.9)
In hospital after birth	958 (66.6)
Midwife	158 (11.0)
Baby's usual doctor	311 (21.6)
Previous pregnancy	473 (32.9)
No advice	76 (5.3)
How often to feed baby	1434 (93.5)
At a class before birth	319 (22.2)
In hospital after birth	993 (69.2)
Midwife	161 (11.2)
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)
Midwife	161 (11.3)
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)
Midwife	166 (11.6)
Baby's usual doctor	279 (19.6)
Previous pregnancy	428 (30.0)
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)
Midwife	141 (9.9)
Baby's usual doctor	287 (20.2)
Previous pregnancy	364 (25.6)
No advice	108 (7.6)
Crying and how to comfort baby	1400 (91.3)
At a class before birth	299 (21.4)
In hospital after birth	613 (43.8)
Midwife	115 (8.2)
Baby's usual doctor	149 (10.6)
Previous pregnancy	485 (34.6)
No advice	243 (17.4)
When to see doctor for well-baby check	1391 (90.7)
At a class before birth	196 (14.1)
In hospital after birth	868 (62.4)
Midwife	121 (8.7)
Baby's usual doctor	314 (22.6)
Previous pregnancy	369 (26.5)
No advice	81 (5.8)

*Respondents could choose as many sources as applicable within each category.

information on a broad range of topics, and 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 underlines the potential positive impact of health care providers in the care of infants.

Limitations

Conducting the survey in large hospitals may have affected the generalizability of our findings to more rural settings. Although we knew the number of completed surveys and the number of potentially eligible neonates, we did not know the number of surveys distributed and could not calculate a true response rate. We received surveys from 17.8% of all visits in the study period. The surveyed population closely reflects the age²⁴ and income²⁵ of Ontario parents, but the surveyed parents were somewhat more educated than average,²⁶ which may represent a response bias. There may have been selection bias in those who chose to complete the survey. The fact that patients requiring resuscitation were excluded may have decreased our numbers of more severe presentations. Recall bias may have affected answers to questions about more remote times, including pregnancy and visits to the emergency department with other children. Comments by emergency department staff may have affected parents' interpretations of the seriousness of the illness compared to their decision to go to the emergency department. Finally, all data were self-reported and could not be correlated to final diagnosis or assessed severity in the emergency department.

Conclusion

Capitalizing on parents' reported confidence by providing families better supports to care for their baby at home or for the infant to be seen elsewhere than at the emergency department may decrease nonurgent emergency department use by neonates. Any such system would need to be immediately responsive, providing same-day support, to have the desired effect. Targeted interventions to decrease emergency department visits for gastrointestinal complaints may have a substantial effect on use, as these were by far the most common, as would community resources to ensure timely assessment for jaundice and support of feeding issues. Further studies are needed to determine which of the common presenting issues — such as jaundice, feeding problems, respiratory issues, crying and rash — may be amenable to education campaigns for families versus those more effectively dealt with through interventions aimed at health care providers or improving community resources.

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