


ORIGINAL ARTICLE

Delayed access to care and late presentations in children during the COVID-19 pandemic New Zealand-wide lockdown: A New Zealand Paediatric Surveillance Unit study

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Aim: Describe paediatricians' experience of adverse health outcomes for children during the New Zealand-wide level 4 lockdown in response to the COVID-19 pandemic.

Methods: Weekly national survey of paediatricians with an open-ended questionnaire.

Results: During the 6-week study survey period, the New Zealand Paediatric Surveillance Unit received 33 reports about 55 instances where paediatricians believed care may have been compromised, about half (56%) relating to infants aged from birth to 6 weeks. Compromised care was for acute presentations in 75%, acute complications of a chronic illness in 14%, with 11% for chronic conditions. Paediatricians reported the outcome as moderately severe (short-term morbidity, increased length of stay, higher level of care) in 38 cases (69%) and in a further 4 (7%) as severe (potential to be life-threatening or result in permanent disability).

Conclusion: Despite clear messaging, hospital avoidance and reduced access to primary and secondary care were associated with significant potential harm for children in New Zealand during a strict lockdown, with newborn infants disproportionately affected. During the implementation of interventions to eliminate community transmission of COVID-19, New Zealand paediatricians note the importance of face-to-face post-natal visits for newborns and primary care services for children with acute illness, to avoid preventable harm.

Key words: community; COVID-19; general paediatrics; health services accessibility; neonatology.

What is already known on this topic

1 Internationally, lockdown measures to mitigate the COVID-19 pandemic have been associated with delays in the presentation to acute care and contributed to serious adverse health outcomes for children with conditions including diabetes mellitus, sepsis and malignancy.

What this paper adds

1 The high proportion of newborns with delayed care for common conditions such as failure to gain weight, jaundice and dehydration was more marked in New Zealand. This experience highlights the importance of direct clinical observation in the assessment of infants and children and should be taken into account in future pandemic planning.

The COVID-19 pandemic has affected the wellbeing of children through direct effects, and even more through socio-economic impacts of measures implemented to control transmission of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).¹ Concern has been raised about the potential for reduced access to appropriate non-COVID-19-related health care, either due to delays in children and parents seeking care, fear of face-to-face consultations on the part of parents or doctors, or as a result of

disruption to health services as they manage and prepare for an influx of mainly adult cases.²⁻⁴ Lower rates of attendance of children to emergency department and paediatric assessment units have been reported in several countries during the COVID-19 pandemic.^{3,5-9}

In response to the threat posed by rising case numbers of SARS-CoV-2 infection, New Zealand implemented a four-level alert system¹⁰ with stringent lockdown¹¹ from 26 March to 28 April 2020 (level 4) followed by continued but less stringent restrictions from 28 April to 13 May 2020 (level 3).¹² Level 4 lockdown started less than a month after the first case of COVID-19 was identified,¹² when there had been 102 cases and no deaths.¹³

From April 2020, the New Zealand Paediatric Surveillance Unit (NZPSU) began weekly surveillance for children hospitalised with SARS-CoV-2 infection. After consultation with other members of the International Network of Paediatric Surveillance Units, the

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NZPSU began weekly surveillance of delayed access or presentation to health services among children and associated health consequences during the lockdown.

The aim of this study was to capture cross-sectional data on the direct and indirect impact of the COVID-19 pandemic and the associated Government response on health outcomes for children, from timely and repeated surveys of New Zealand paediatricians.

Methods

Established survey mechanisms of paediatric surveillance¹⁴ were used to prospectively ascertain cases where paediatricians perceived adverse effects of delayed access to care during the COVID-19 national lockdown. The NZPSU electronic reporting card is sent to around 250 paediatricians (approximately 83% of all paediatricians registered with the New Zealand Medical Council) with typical response rates of 70–80% each month.

The case definition used for this study was: 'Any child where the responsible paediatrician felt there had been a delay longer than what they would normally expect in a child's hospital presentation, admission, clinical review, investigation, treatment or discharge, or a complication, that may be due to the COVID-19 pandemic'. This COVID-related survey was sent out weekly between 15 April and 20 May 2020, and following notification of a potential case, a unique link to an online questionnaire was sent to the reporting paediatrician. Anonymous information requested included age and gender of the case, acuity of the condition, how the delay might be associated with the COVID-19 pandemic, outcomes and free text details of the case. Severity was defined as minor (resulting in inconvenience, patient or family dissatisfaction), moderate (short-term morbidity, increased length of stay, higher level of care), or severe (life-threatening event, permanent disability or death). After 6 weeks, when New Zealand dropped down COVID-19 alert levels and usual outpatient and community services resumed, the survey was discontinued. By that time, no new types of event were being reported, so in qualitative terms a data saturation point had been reached.

Study data were collected and managed using REDCap electronic data capture tools hosted at the University of Otago.^{15,16} Descriptive data are presented with counts and percentages, alongside content analysis of free-text data. Ethical approval for this research was granted by the Southern Health and Disability Ethics Committee.

Results

During the 6-week study period, 34 reports of instances of potential delay in care were received from 31 paediatricians. One report was a general observation that 'all the children due for outpatient review over that time had delayed care' (Report 34) and was not included in further analysis. The remaining 33 reports provided data on 55 cases that met the study case definition.

Case features

Cases were reported from all four health regions with no apparent clustering.

In 13 cases (24%), outcomes of the delay corresponded to the study definition of minor impact, including seven related to

cancelling of outpatient clinics and elective procedures. One report highlighted a greater impact where appointments were already overdue, and for culturally and linguistically diverse populations.

... One delay has been for families where English is a second language, so phone consults are not possible. This case was a child ... who was overdue for paediatric review, which was further delayed due to COVID situation (Report 31, acute complication of a chronic illness, age 10–14 years).

The remaining reports concerned children where delay met study definitions of harm that was moderate (38 cases, 69%) or severe (4 cases, 7%).

Thirty-six cases (65% of all cases) were infants in the first year of life, most aged less than 6 weeks. There was an even spread of cases among older age groups (Fig. 1).

Overall, the most common issues reported related to acute conditions in the perinatal period (49%) (Table 1).

Over the course of Level 4, our service admitted a significant excess of neonates (15) with jaundice and/or dehydration requiring treatment (Report 29, 15 cases with acute presentation, age 1–6 weeks).

The most serious conditions arising in the perinatal period were two cases of hypoxic-ischaemic encephalopathy due to birth asphyxia following delayed delivery, and a case of necrotising enterocolitis where some treatment options were not available.

A range of conditions was impacted by delay in paediatric care in older children. A case with gastroenteritis resulted in severe impact, when hospital avoidance was associated with severe hypernatraemic dehydration and metabolic acidosis (Report 5, acute presentation, age 6 weeks–1 year). Conditions resulting in moderate impact included type 1 diabetes mellitus, infections (cellulitis, septic arthritis), and acute exacerbations of chronic conditions such as epilepsy and cystic fibrosis. Moderate impact was reported for four cases of rheumatic fever who presented in one hospital.

This is the number of new RF [rheumatic fever] cases usually seen in a year ... Sore throat programmes that normally operated in local schools were stopped by the COVID-19 lockdown (Report 24, four cases with acute presentation, age 5–14 years).

Perceived role of pandemic response

Review of free text fields of cases where the impact of delay was moderate or severe identified themes of hospital avoidance, reduced access to health care, and lack of face-to-face post-natal visits as factors associated with these cases. Two reports where respiratory symptoms in adult carers impacted on the timeliness of care were the only instances where delay was directly associated with the COVID-19 pandemic. One case was in the perinatal period, and the other a young infant where assessment of non-accidental injury was delayed.

The obstetric focus was on the suspect COVID-19 rather than on the fetal distress ... resulting in a delay in delivery of the baby. (Report 18, acute presentation, perinatal).

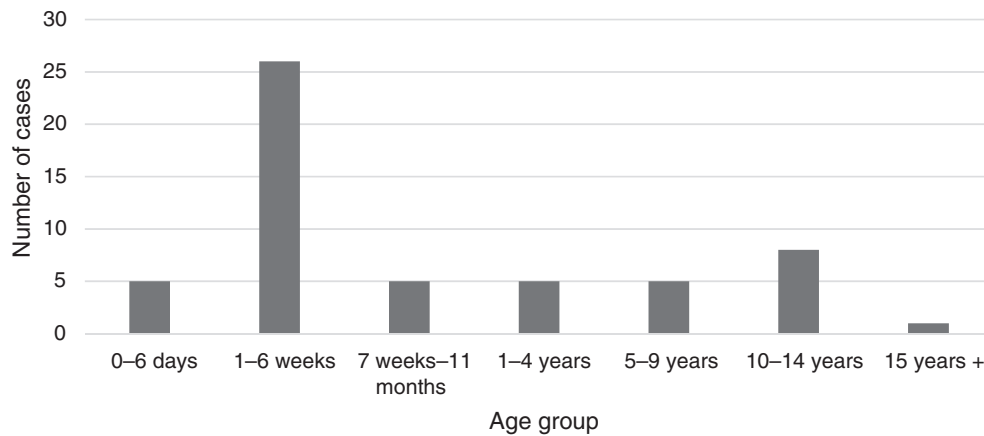


Fig 1 Case reports of delay in paediatric care perceived by paediatricians, by age group, New Zealand May–June 2020.

Table 1 Case reports of delay in paediatric care perceived by paediatricians, by condition and severity of impact, New Zealand May–June 2020

Diagnostic group	Minor impact, n	Moderate impact, n	Severe impact, n	Total number of cases (%)
Perinatal/Neonatal conditions	1	24	2	27 (49)
Severe anaemia			1	1 (2)
Gastroenteritis			1	1 (2)
Diabetes (type 1)		2		2 (4)
Other endocrine, nutritional and metabolic diseases		1		1 (2)
Congenital anomaly	2	1		3 (5)
Rheumatic fever/Rheumatic heart disease	1	4		5 (9)
Injury (assault)	1	1		2 (4)
Nervous system disease	1	1		2 (4)
Digestive system disease	1	1		2 (4)
Musculoskeletal disease (including septic arthritis)		2		2 (4)
Skin infection		1		1 (2)
Other conditions or not specified	6			6 (11)
Total	13	38	4	55 (100)

Diagnostic groups based on the international statistical classification of disease and related health problems 10th revision Australian modification (ICD-10-AM) chapter and block headings. Minor impact = inconvenience, patient/family dissatisfaction; moderate impact = short-term morbidity, increased length of stay, higher level of care; severe impact = life-threatening event, permanent disability, death.

... COVID testing needed [for parent] that day ... COVID result delayed - had to be put off for 48 hours in total. [Delay] didn't change outcome for this child ... However - had potentially serious implications. (Report 33, acute presentation, age 6 weeks–1 year).

Patient ... was advised to come to hospital ... Parents received advice from another health professional not to come to hospital for assessment due to the COVID-19 risk ... The recognition of electrolyte disturbance was delayed by 2 weeks. This was potentially dangerous ... (Report 19, Child with acute exacerbation of chronic illness, age 1–6 weeks).

Hospital avoidance

The history elicited by paediatricians who responded to the survey identified concerns about the safety of hospital settings from parents and from primary care health practitioners.

Seems very likely either from family, midwife, or possibly hospital that the reason for delay in presentation for delivery to the hospital likely due to fear of COVID exposure in hospital setting (Report 3, acute condition, perinatal).

Changed access to primary care

Histories elicited from children and families indicated that changes in access to primary care services were significant factors in delayed paediatric care. Early discharge from hospital after delivery may have exacerbated the effects of reduced post-natal observation:

Midwife had not been able to assess at home since birth. Hence ended up with a hospital admission where earlier community assessment, guidance & intervention would have probably prevented that. In each case family had refused to allow midwife in for regular postnatal assessments due to fear that they'd 'bring COVID in' to the house. (Report 17, six acute presentations, age 1–6 weeks).

In other cases parents were unable to access primary care, despite significant concerns for the health of their children, for example:

[Child] Unwell and lethargic ... Called GP [General Practitioner] for appointment as concerned for child, but offered phone consultation only. Thought to be viral infection and told to stay home. Called [twice more]. Told still likely viral over the phone ... As last attempt drove child to another GP practice to seek face to face consultation ... sent to hospital in Severe Diabetic Ketoacidosis. (Report 21, acute presentation, age 1–4 years).

Outcome

A number of significant negative health outcomes were reported, including extended hospital stays and need for intravenous antibiotics or intensive care which may not have been required if seen earlier.

would have most likely died within hours in the community if not sent to hospital by [health professional] who incidentally spotted [them] while visiting a family member (Report 5, acute presentation, age 6 weeks–1 year).

Discussion

This prospective study highlights new data and unintended risks to children and families as a consequence of COVID-19 lockdown restrictions and associated health care disruption. Over the 6-week period of New Zealand-wide lockdown, a considerable spectrum of harm and potential harm occurred to children and their families due to hesitancy on their part to access health care, in some cases reinforced by professionals, or of primary care or secondary care to provide care. In a number of cases, this led to severe and long-term consequences for those children and families involved. Over this period the NZPSU received no reports of children who were admitted to hospital with SARS-CoV-2 infection.

Paediatricians' perceptions were that families considered the risk of COVID-19 infection in hospital posed greater risk to their child than the current health condition, with similar concerns from some health professionals who advised against hospital attendance. The mortality risk associated with SARS-CoV-2 infection for children is lower than that observed in the 2009 H1N1 pandemic.¹⁷ There was also the perception that some primary health-care providers were hesitant to provide face-to-face assessment, and were quick to interpret children's symptoms, as conveyed during phone consultations, as self-limiting viral infections.

In a similar paediatrician survey in the UK, the most commonly observed condition with adverse consequences of delay in care was diabetes mellitus (44 among 141 main conditions).³ In a hospital-based study from Italy, sepsis was reported in 6 of 12 cases of delayed care, of whom 3 died.² In contrast, 31 of the 55 cases notified in New Zealand occurred in the first 6 weeks of life, with the majority of these presenting with combinations of failure to gain weight, jaundice, and dehydration. Neonatologists in the UK also reported concerns about poor neonatal outcomes as a result of late presentations and early hospital discharges, but these cases comprised only 8 of the 141 main conditions where delayed presentation was considered to be a contributing factor.³

The 'bubble' concept that was credited with making New Zealanders aware of the importance of social distancing,¹⁸ may have had the unintended consequence of parents excluding midwives from their homes and their infants not having important post-natal observation. The official government advice that Well Child Tamariki Ora services (a free service provided by The Ministry of Health for all New Zealand children from birth to 5 years)¹⁹ would usually be provided by telephone or video during higher alert levels²⁰ sought to balance risk to the frontline workforce with the need to maintain well child surveillance. New parents may not always have the experience to recognise and report medically significant signs in their infants, especially when kept socially distanced from wider family and community supports. The observation of adverse health consequences for these youngest infants is important for future health planning. The perinatal period through to early infancy is one of considerable vulnerability to illness with high hospitalisation rates,²¹ and a critically important developmental period that sets up the foundation for health and wellbeing across the lifecourse.²² Lockdowns may result in significant hidden harms for infants and young children that vary depending on family background and circumstance.²² Conversely, parts of New Zealand noted unexpected benefits of lockdown with a dramatic decrease in hospitalisations of young infants with lower respiratory tract infections during the 2020 winter, compared with previous years.²³

Strengths of this study include the prospective nature of the data collection using the well-established format of the NZPSU network, which has comprehensive reach into paediatric secondary and tertiary level hospital care. Given the hospital-based data collection, cases of more significance were able to be collected. As cases were reported only by paediatricians, this is likely an underestimate and more issues may have been dealt with in primary care or by other hospital specialists. In particular family violence and child abuse may have been underreported while families were isolated at home. The reported perceptions of treating paediatricians cannot establish causation.

Overall, these data are valuable in efforts for service improvement given the ongoing nature of potential rolling lockdowns and community members and health-care professionals both experiencing anxiety and potential service disruption. These data suggest a more nuanced and balanced message to primary care and the community about access to care, particularly given the ongoing nature of the COVID-19 pandemic. Future pandemic responses will need adequate funding of public health services²⁴ so that essential and time-critical child health surveillance can

continue without redeployment of this workforce to other functions. Further work is needed to identify the impact of the pandemic response on health equity, using patient-identified ethnicity and markers of socio-economic deprivation.

Conclusion

Reducing the movement of individuals and families when there is a high likelihood of community transmission has been a key component of the COVID-19 pandemic response. In this context, the health needs of infants and children must be met. Despite clear messaging about access to health care as an essential service, hospital avoidance and reduced access to health care contributed to moderate and severe harm for infants and children in New Zealand. Facilitating face-to-face post-natal visits, ensuring access to primary care services in the community for children with acute illness, and clear messaging about how hospitals maintain safety for all patients are important strategies to mitigate unintended adverse effects of lockdown.

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References

- United Nations Sustainable Development Group. *The Impact of COVID-19 on Children*. Internet: United Nations; 2020.
- Lazzerini M, Barbi E, Apicella A, Marchetti F, Cardinale F, Trobia G. Delayed access or provision of care in Italy resulting from fear of COVID-19. *Lancet Child Adolesc Health* 2020; **4**: e10–1.
- Lynn RM, Avis JL, Lenton S, Amin-Chowdhury Z, Ladhani SN. Delayed access to care and late presentations in children during the COVID-19 pandemic: A snapshot survey of 4075 paediatricians in the UK and Ireland. *Arch. Dis. Child.* 2020; **106**: e8.
- Snapiro O, Rosenberg Danziger C, Krause I *et al.* Delayed diagnosis of paediatric appendicitis during the COVID-19 pandemic. *Acta Paediatr.* 2020; **109**: 1672–6.
- Isba R, Edge R, Jenner R, Broughton E, Francis N, Butler J. Where have all the children gone? Decreases in paediatric emergency department attendances at the start of the COVID-19 pandemic of 2020. *Arch. Dis. Child.* 2020; **105**: 704.
- Scaramuzza A, Tagliaferri F, Bonetti L *et al.* Changing admission patterns in paediatric emergency departments during the COVID-19 pandemic. *Arch. Dis. Child.* 2020; **105**: 704–6.
- Chong S-L, Soo JSL, Allen JC *et al.* Impact of COVID-19 on pediatric emergencies and hospitalizations in Singapore. *BMC Pediatr.* 2020; **20**: 562.
- McDonnell T, Nicholson E, Conlon C *et al.* Assessing the impact of COVID-19 public health stages on paediatric emergency attendance. *Int. J. Environ. Res. Public Health* 2020; **17**: 6719.
- Dann L, Fitzsimons J, Gorman KM, Hourihane J, Okafor I. Disappearing act: COVID-19 and paediatric emergency department attendances. *Arch. Dis. Child.* 2020; **105**: 810–1.
- New Zealand Government. *New Zealand COVID-19 Alert Levels Summary*. 2020. Wellington: New Zealand Government. Available from: <https://covid19.govt.nz/assets/resources/tables/COVID-19-alert-levels-summary.pdf> [accessed October 2020].
- Robert A. Lessons from New Zealand's COVID-19 outbreak response. *Lancet Public Health* 2020; **5**: e569–70.
- Jefferies S, French N, Gilkison C *et al.* COVID-19 in New Zealand and the impact of the national response: A descriptive epidemiological study. *Lancet Public Health* 2020; **5**: e612–23.
- Cousins S. New Zealand eliminates COVID-19. *Lancet* 2020; **395**: 1474.
- Grenier D, Elliott EJ, Zurynski Y *et al.* Beyond counting cases: Public health impacts of national paediatric surveillance units. *Arch. Dis. Child.* 2007; **92**: 527–33.
- Harris P, Taylor R, Minor B *et al.* The REDCap consortium: Building an international community of software partners. *J. Biomed. Inform.* 2019; **95**: 103208.
- Harris P, Taylor R, Thielke R *et al.* A metadata-driven methodology and workflow process for providing translational research informatics support. *J. Biomed. Inform.* 2009; **42**: 377–81.
- Muscattello DJ, McIntyre PB. Comparing mortalities of the first wave of coronavirus disease 2019 (COVID-19) and of the 1918-19 winter pandemic influenza wave in the USA. *Int. J. Epidemiol.* 2021; **49**: 2089–91.
- Ingham T. *Bubble Concept Goes Viral*. Dunedin: University of Otago; 2020. Available from: <https://www.otago.ac.nz/hekitenga/2020/otago742700.html> [accessed February 2021].
- Conectus. *The Well Child Tamariki Ora Programme*. Auckland: School of Population Health, University of Auckland; 2016. Available from: <https://www.wellchild.org.nz/> [accessed February 2021].
- Ministry of Health. *COVID-19: Well Child Tamariki Ora*. Wellington: The Ministry; 2020. Available from: <https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-information-health-professionals/covid-19-well-child-tamariki-ora> [accessed February 2021].
- Simpson J, Duncanson M, Oben G *et al.* *The Health Status of Children and Young People in New Zealand 2015*. Dunedin: New Zealand Child and Youth Epidemiology Service, University of Otago; 2016.
- Reed J, Parish N. *Working for Babies. Lockdown Lessons from Local Systems*. London: Parent-Infant Foundation, First 1001Days Movement; 2021.
- Trenholme A, Webb R, Lawrence S *et al.* COVID-19 and infant hospitalizations for seasonal respiratory virus infections, New Zealand, 2020. *Emerg. Infect. Dis.* 2021; **27**: 641–3.
- Skegg D. The Covid-19 pandemic: Lessons for our future. *Policy Q.* 2021; **17**: 3–10.