

# Children who 'grow up' in hospital: Inpatient stays of six months or longer

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**OBJECTIVE:** To describe the clinical course of all infants and children hospitalized for six consecutive months (180 days) or longer at a tertiary/quaternary children's hospital in Western Canada.

**METHODS:** A retrospective review of medical records for all eligible patients from January 1, 2007 to December 31, 2012 at Stollery Children's Hospital (Edmonton, Alberta) was performed.

**RESULTS:** A total of 61 patients experienced 64 eligible hospitalizations. The mean length of stay was 326 days, corresponding to a cumulative 20,892 hospital days (57.2 patient-years). Prevalent procedures resulting in long hospitalization were long-term tracheostomy ± ventilation in 32 (52%) patients, need for organ transplantation in 24 (39%) with completed transplantation in 15 (25%), and ventricular-assist devices (VADs) in seven (11%). Sixteen (26%) patients in the study group died, and 16 (26%) were placed in long-term care or out-of-home care at the end of their long hospitalization. Of children displaced from their family home, 14 (88%) were Aboriginal.

**CONCLUSION:** Infants and children who experience very long hospitalizations have complex illnesses, with substantial risk for mortality and a high rate of displacement from their families after discharge. Aboriginal children appear to be particularly vulnerable to displacement and problem solving for this population must be undertaken, involving a variety of stakeholders.

**Key Words:** *Chronic illness/condition; Decision making; Family impact; Hospitalization; Infant*

Over the past several decades, the number of children receiving mechanical ventilation and the number of paediatric intensive care unit (PICU) beds has dramatically increased in developed countries. A recent study conducted in the United States showed that the incidence of mechanical ventilation in hospitalized children almost doubled between 1991 and 2001, from 77 per 1000 hospitalizations in 1991 to 124 per 1000 in 2001 (1). Simultaneously, novel life-sustaining therapies have come into mainstream clinical use, including extracorporeal membrane oxygenation (ECMO), ventricular assist devices (VADs), and increasingly complex solid organ transplantations such as neonatal cardiac transplants and multivisceral transplants for short bowel syndrome. Children with chronic complex conditions account for a steadily increasing proportion of hospitalized paediatric patients and health care resource consumption (2). Two decades ago, a long hospitalization of a child was considered to be >1 week (3). Currently, long hospitalizations are counted in months and even years. Increasing length of stay and acuity of stay has been well documented at the Stollery Children's Hospital in Edmonton, Alberta, in the neonatal intensive care unit (NICU), PICU and wards (internal documents), which is similar to

Les enfants qui « grandissent » à l'hôpital : les séjours hospitaliers de six mois ou plus

**OBJECTIF :** Décrire l'évolution clinique de tous les nourrissons et les enfants hospitalisés pendant au moins six mois consécutifs (180 jours) dans un hôpital de soins tertiaires et quaternaires de l'Ouest canadien.

**MÉTHODOLOGIE :** Les chercheurs ont effectué une analyse rétrospective des dossiers médicaux de tous les patients admissibles du *Stollery Children's Hospital* d'Edmonton, en Alberta, entre le 1<sup>er</sup> janvier 2007 et le 31 décembre 2012.

**RÉSULTATS :** Au total, 61 patients ont vécu 64 hospitalisations admissibles. Leur séjour hospitalier moyen durait 326 jours, pour un séjour cumulatif de 20 892 jours d'hospitalisation (57,2 années-patient). Les principales interventions ayant suscité ces longues hospitalisations s'établissaient comme suit : trachéostomie ± ventilation à long terme chez 32 patients (52 %), besoin d'une greffe d'organe chez 24 patients (39 %) et greffe complétée chez 15 patients (25 %), et dispositif d'assistance ventriculaire chez sept patients (11 %). Seize patients (26 %) du groupe d'étude sont décédés, et 16 (26 %) ont été placés en soins de longue durée ou en foyer d'accueil à la fin de leur longue hospitalisation. Parmi les enfants déplacés de leur milieu familial, 14 (88 %) étaient Autochtones.

**CONCLUSION :** Les nourrissons et les enfants qui sont hospitalisés très longtemps ont des maladies complexes, qui s'associent à un risque de mortalité important et à un taux élevé de déplacement du milieu familial après le congé. Les enfants autochtones semblent particulièrement vulnérables à de tels déplacements. Il faudra chercher à résoudre ce problème au sein de cette population, avec la participation de divers intervenants.

the trends of other tertiary/quaternary paediatric hospitals (4). Despite this, very little research has been published about these patients and their families. One study involving infants who were hospitalized from the neonatal period for ≥6 months revealed a primary theme of "doing the wrong thing" on the part of health care professionals who cared for these infants. Another important finding was that 23% of these infants no longer had ongoing contact with their parents, who had been overwhelmed by the demands of their medical care (5). The purpose of the present study was to describe the population of children who experienced a very long hospital stay. Although beyond the scope of the present study, better understanding this patient population is important because of the inevitable impact long hospitalization has on children, their families and health care resource utilization.

## METHODS

A retrospective study was undertaken of all infants and children who were hospitalized at the Stollery Children's Hospital in Edmonton, Alberta between January 1, 2007 and December 31, 2012, for 180 consecutive days or longer. The present study was

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**TABLE 1**  
**Characteristics of patients hospitalized for**  
**≥180 consecutive days**

Patient characteristic	Total	Alive	Deceased
Patients	61* (100)	45 (74)	16 (26)
Male sex	34 (56)	25 (41)	9 (15)
Female sex	27 (44)	20 (33)	7 (11)
Age at admission			
≤30 days	37 (61)	28 (46)	9 (15)
30 days to ≤1 year	10 (16)	9 (15)	1 (2)
1 to ≤5 years	4 (7)	1 (2)	3 (5)
5 to ≤12 years	5 (8)	4 (7)	1 (2)
>12 years	5 (8)	3 (5)	2 (3)
Cardiac disease	17 (28)	10 (16)	7 (11)
Multiple congenital anomalies	10 (16)	8 (13)	2 (3)
Short bowel syndrome	9 (15)	6 (10)	3 (5)
Neurological/neuromuscular disease	7 (11)	6 (10)	1 (2)
ICU stay ≥2 months (total)	41 (67)	30 (49)	11 (18)
ICU stay <2 months (total)	19 (31)	16 (26)	3 (5)
No ICU stay	1 (2)	0 (0)	1 (2)
Awaiting solid organ transplant	24 (39)	16 (26)	8 (13)
Completed solid organ transplant	15 (25)	11 (18)	4 (7)
Tracheostomy ± ventilator	32 (52)	27 (44)	5 (8)
Isolated airway anomaly	6 (10)	6 (10)	0 (0)
Tracheostomy excluding patients with isolated airway anomaly	26 (43)	21 (34)	5 (8)

*Data presented as n (%). \*61 patients had 64 eligible hospitalizations: one patient had three stays of >180 days and is alive, and another had two stays and is deceased. The denominator for the results is the number of patients, not the number of hospitalizations. For children with repeat hospitalizations, data represent the first eligible stay. ICU Intensive care unit*

approved by the Health Research Ethics Board at the University of Alberta. The Stollery Children's Hospital is a tertiary/quaternary children's hospital with a local catchment of 1.2 million. At the beginning of the study period in 2007, there were 133 beds, which had increased to 146 beds by the end of 2012 when the study concluded (mean 137 beds/year). This includes all ward/PICU/NICU beds. This centre performs all open-heart surgery for the prairie provinces and the far north of Western Canada (catchment area approximately 6 million), as well as all solid organ transplantations (cardiac, renal, hepatic and multivisceral) for all of Western Canada (catchment area approximately 10 million). This hospital offers a paediatric ECMO program, including a mobile ECMO transport service for patients within the larger catchment area. Our system does not capture transfer events between the wards and the PICU; thus, we only sought to assess total number of PICU days (either <2 months or ≥2 months) due to the constraints of manually counting days in the chart.

A list of all eligible patients was generated by a health information analyst through an automated system. For patients who had >1 eligible hospitalization, results were reported as per the total number of patients, not the total number of hospitalizations. A case report form was devised within REDCap database (Vanderbilt University, Tennessee, USA), and all charts were reviewed such that required data elements were captured for all patients. This included demographic information, primary and secondary diagnoses, major medical treatments undertaken and discharge disposition. A zero as the second position within their postal codes identified patients living in a rural setting. All demographic information, admission histories, medical consultations and discharge summaries were examined in detail. The first three charts were reviewed together by two of the authors (DD and TW) to ensure

consistency of completing the case report form. Subsequently, charts were reviewed by either DD or TW, but notations were made to the case report form to confer whenever there was uncertainty regarding how to categorize data.

Patients were presumed to be alive unless their death had been reported to the bereavement service for the hospital, which captures all neonatal and paediatric deaths at this hospital, as well as children who die in the Edmonton area who are receiving home care services. This bereavement registry is double-checked quarterly with health information analysts to ensure no deaths in the hospital are unreported.

#### Data analysis

Summary statistics, including mean or median and SDs or ranges, were provided for continuous variables (ie, age) and frequency distributions were used to summarize all categorical patient data (eg, sex). SPSS version 19.0 (IBM Corporation, USA) was used for this analysis.

### RESULTS

During the study period, there were 7230 (range 6953 to 7637) hospital inpatient admissions/year, with a mean length of stay of 6.1 days (range 5.7 days to 6.5 days). During the same time, there were 762 (range 666 to 833) PICU admissions/year, with a mean length of stay of 6.6 days (5.7 to 7.4 days). During this time, there were 64 hospitalizations of 61 patients that exceeded 180 consecutive days. One child experienced three such hospitalizations and another experienced two. Hospitalizations lasted a mean of 326 days (range 181 to 984 days). Cumulatively, they accounted for 20,892 patient-days (57.2 patient-years). In this 137-bed hospital, over six years (300,030 patient-days), this translates to bed occupancy by these 61 patients of 7% annually. Characteristics of this patient group are summarized in Table 1. As indicated by postal code, 11 children (18%) were from out of province, and 19 (31%) were from rural areas. Thirty-three patients (54%) were from the greater Edmonton area.

All children in the study underwent at least one invasive life-saving therapy, except one child admitted for complex palliation. Thirty-two (52%) children in the study had a long-term tracheostomy, with or without chronic ventilation. In Alberta, the standard of care for a dependent child with a tracheostomy is attendance by an awake overnight caregiver who can intervene in the case of unexpected airway emergency. Thirty of the 32 (94%) patients with a tracheostomy had prolongation of their hospitalization for >1 month beyond the planned discharge date due to difficulty in finding suitable community care that could meet this standard. Nine of these 32 patients (28%) were unable to return to their home and were transferred to a local community placement to provide this care. Of these nine children, only one was from the Edmonton area, and four were from remote First Nations reservations. Six of seven children who were supported with a VAD during the prolonged hospitalization went on to undergo cardiac transplantation, with the other child successfully weaned off the VAD, obviating the need for transplantation. Other specific therapies that contributed to prolonged hospitalization were dialysis or other forms of renal replacement therapy, long-term total parenteral nutrition and related complications, noninvasive ventilation and complex wound care.

From a decisional/psychosocial perspective, consultation with the clinical ethics service occurred for five (8%) patients. Twenty-four (39%) children had involvement of psychiatry services during their time in hospital. Of these, 12 (50%) children were assessed for concerns about depression or anxiety. Two children were diagnosed as having significant attachment problems. The

remaining consultations occurred primarily because of concerns about delirium. Involvement of Child and Family Services regarding parenting concerns was documented for 18 (30%) patients. Palliative care consultation occurred for 14 (23%) children, and for seven of 16 (44%) of the children who subsequently died. After hospital discharge, three (5%) children went home with few or no health support needs in the community. Thirty-four (56%) had health needs requiring support in the home setting after discharge, ranging from one child requiring around-the-clock supervision by two caregivers, to more modest supports such as home nutrition support for tube feeding; home nursing care; physical, occupational or speech therapy; social work; or early intervention programming. Sixteen patients (26%) were not able to return to their family home because their care needs were unable to be met in that environment. Ten (16%) children required placement in a medical out-of-home or foster care arrangement and five (8%) were transferred to a long-term care facility. One child, readmitted for <180 days when the study closed, remains in hospital with a current stay of 664 days and counting, now waiting for out-of-home medical placement. Of note, 14 of 16 (88%) of the children for placement out of the home were Aboriginal, compared with the general population, of which approximately 5% are of Aboriginal ethnicity.

Seven (11%) children died at the end of their long hospital stay, but by study closure in 2012, 13 (21%) children had died, with an additional three dying subsequently, yielding a total of 16 (26%). Six children in the study group had isolated airway anomalies requiring tracheostomy. Previous studies reveal that these children are at lower risk for death than those with complex conditions requiring tracheostomy (6). If these six children are excluded from mortality calculations, the adjusted mortality rate increases to 29%.

## DISCUSSION

Although a preliminary descriptive study, the present research provides novel information regarding the increasingly common phenomena of prolonged paediatric hospitalization in Canada. The sheer magnitude of the numbers pertaining to length of stay, geographical separation of children and families, morbidity and death is, perhaps, a wake-up call for those involved in paediatric inpatient care to more mindfully anticipate the possible trajectories of patients.

Unfortunately, contemporary hospital paediatric care is often organ based, fragmented and discontinuous. As such, there are frequently large gaps in the narrative of the patient's story from any one clinician's perspective, thereby shifting the focus from the patient's evolving trajectory of illness to the day-to-day minutiae of one small segment of their journey. This intermittent model of health care delivery exposes patients and families to many different doctors, each of whom has time-limited responsibility and interaction. The fact that fully one-half of our patients, who have had the longest hospital stays, either died or were displaced from their family home is alarming. There are few clinicians or parents who would consider this to be an acceptable outcome, especially when one considers the experience of that child and family, and all that they endured leading up to this eventuality. The fact that this is occurring, however, may be more difficult to recognize when responsibility for the patient is only intermittent. Our findings argue strongly for the importance of a main primary physician who oversees and coordinates the care of each patient with complex illness.

Some may argue, considering the corollary, that one-half of patients had an apparently more favourable outcome, and there is no way of distinguishing the children who will do well from those who will not. It is true that, despite knowing factors predictive of long stays and increased mortality, these have limited utility in helping make clinical decisions for an individual patient. However,

large longitudinal studies do provide some insight. The reduction in PICU mortality since the early 1980s has occurred proportionally at the expense of a significant increase in survivors with moderate to severe disability (7). Furthermore, there is an increased risk for poor outcome and mortality for long stays of neonates and very young infants <3 months of age, for those with comorbid conditions and for those with pre-existing moderate to severe disability (8,9). Namachivayam et al (8) concluded that more than two-thirds (67%) of children who stay in the PICU for  $\geq 28$  days have unfavourable outcomes (moderate or severe disability, or death), and that because of consistency among similar large studies, the findings are likely a reasonable estimate of paediatric intensive care performance in Western societies. Similar to the present study, they also found that one-half of children who died were initially discharged successfully.

With regard to resource utilization, a study from Ontario determined that, although representing only 0.67% of the child population within the province, children with complex chronic medical needs accounted for almost one-third of all child health costs (10). The same study indicated that children with technological assistance in the community consume a high portion of home care supports. Educational needs over the child's lifetime are also impacted, with a recent local study indicating that developmental delay and cognitive deficit are frequent sequelae for children who have received complex therapies at our hospital (11). The need to inform parents about outcomes beyond mere survival is increasingly being identified by follow-up services for children who have received complex therapies (6,11).

The most frequent invasive therapy in this group was long-term tracheostomy and ventilation. This is mirrored by the impressive increase in the number of young children supported by home mechanical ventilation and concomitant PICU stays reported by others (12). While tracheostomy is sometimes considered to be a fairly 'simple' procedure, the ramifications for these children and their families are significant, with almost every aspect of life profoundly affected, and life a constant tension between distress and enrichment in caring for these children at home (13).

One-quarter of the children in our study were discharged to a nonhome environment. How much or little weight this should carry in the assessment of the child's best interest was beyond the scope of the present study, but we found the frequency with which this occurred to be disturbing. It was not apparent from the documentation in the medical record that the possibility (or even probability) that a child would never be able to return to his family, especially those living remotely or on reserve, was discussed at the time that life-saving therapies were being considered. Rather, documentation in clinical progress and social work notes reflected concern about the ultimate discharge disposition of the child from hospital as the likelihood of discharge became more imminent. The involvement of Child and Family Services, Alberta's child protection service, in almost one-third of cases appears to be very high compared with that of hospitalized children in general, and speaks to the extraordinary needs of many of these children in planning for a transition to home. Unfortunately, neither our hospital nor Child and Family Services tracks which hospitalized children have Child and Family Services involvement; thus, it was not possible to compare the study group with the proportion of all hospitalized children who require this service. The proportion of our study population that was ultimately discharged to a nonhome setting was similar to that in a study by Catlin (5) involving neonates with complex illness in the United States.

Of particular concern is the over-representation of Aboriginal children, many of whom were from rural and remote reservations.

Health care on First Nations (Aboriginal) reservations in Canada is a federal jurisdiction, while health care delivery for the general population is a provincial responsibility. Aboriginal children, therefore, cannot benefit from many home health services that are available off reserve in the province. This disconnect in services is well documented, and has resulted in a standard known as 'Jordan's Principle' (14). Our findings suggest that care for First Nations children with complex needs after discharge is an ongoing systems problem that requires immediate attention. Further exploration and problem solving appears to be required with collaboration among First Nations leaders, government, health and social services systems.

The 'early' mortality rate of 26% after at least one lengthy hospitalization is troubling, given the burden incurred to the child, family and health care system through the long course of medical treatment that preceded death, of which this prolonged hospitalization is just one feature. This finding is consistent with a prevailing narrative of rescue that has been noted in contemporary North American health care (15), and in other studies that evaluated outcomes of children with complex chronic conditions (2). The number of children who have died may have been underestimated in the present study because almost one-half of the study group lived out of the Edmonton area and, therefore, deaths of children no longer followed by the hospital would not necessarily have been reported.

Considering all of these findings, it would appear that for this small but important population of children with chronic complex conditions, there is an imbalance between intervention and outcome. One suggestion is that all children who have diagnoses that infer long hospitalization from the outset be treated differently than the overwhelming majority of patients who are admitted for only a few days or weeks. This may necessitate shifting the way we deliver care to these patients and creativity regarding how authentic continuity of care can be realized. Our findings support the adoption of formalized processes for making difficult decisions by multidisciplinary teams when caring for a child for whom very long-term hospitalization is likely, and will remain at high risk for permanent illness, disability or death. The goal of doing so is to improve long-term outcomes and enhance satisfaction of all involved.

The present study was limited by its retrospective nature; this was complicated by the fact that a majority of medical records had been converted to microfiche as a single continuous reel, with an inaccessible paper source document. Certain data elements (eg, the type of decision-making processes and impact on parents) were

excluded from the study because they were too difficult to find reliably for every patient. The present study was also limited because it considered only one institution; therefore, findings may not be generalized to other tertiary/quaternary care centres for children. Future studies, as suggested by other authors, should be prospective, multicentre collaborations, tracking the eventual outcomes of all patients with long stays (7,8). Although such research may be costly, it is warranted, given the unintended suffering experienced by these patients and their families, and the significant resources they consume, especially when one-half of them may die or be displaced.

## CONCLUSION

Infants and children who experience extremely long hospitalizations have complex illnesses and comorbidities, with substantial risk for mortality and a high rate of displacement from their families after discharge. Of note, Aboriginal children appear to be particularly vulnerable to displacement, and problem solving for this population needs to be performed at multiple levels with a variety of stakeholders.

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**CONTRIBUTOR'S STATEMENT:** Dawn E Davies conceptualized and designed the study, drafted the initial manuscript, revisions, and approved the final manuscript as submitted. Dawn E Davies and Tara Wren designed the data collection instruments, performed all data collection, critically reviewed the manuscript, and approved the final manuscript as submitted. Dawn S Hartfield performed the initial analyses, reviewed and revised the manuscript, and approved the final manuscript as submitted. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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