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# TABLE OF CONTENTS

## ***Editorial***

1. Vaccinate? There should be no question e3-e4  
*– Teresa Castro Twomey\**

## ***Editorial***

2. Medication Reconciliation in the Pediatric Emergency Room e5-e6  
*– Praneetha Chaganti and Anita Siu\**

## ***Editorial***

3. The Journal of Pediatrics and Neonatal Nursing: A Forum for Ideas, Innovation, and Illumination e7  
*– John E. Nathan\**

## ***Research***

4. Burden of Illness for Neural Tube Defects: Canadian Perspective 26-36  
*– Gideon Koren, Floortje van Nooten, Randall Winnette, Paige Church, Radek Wasiak\*, Parvaneh Yazdani-Brojeni, Min Hua Jen, Dimitra Lambrelli, Mark Jedd and Marion Kissner*

## ***Research***

5. Reflexion about Pediatrics, Anesthesia and Education in Pediatric Anesthesia in Colombia and South America 37-42  
*– Piedad Echeverry\**

## ***Review***

6. Nursing Care of Infants and Children with Bronchiolitis 43-49  
*– Hala Mohamed Assem\**

## Editorial

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## Vaccinate? There should be no question

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As a child, my parents never thought twice about whether or not my siblings and I would get our vaccinations, we just got them. I don't know if my mother's decision was in part because she was a nurse or if it was just the right thing to do as a parent. But as an adult, I'm thankful she made the decision to vaccinate us. I never have to worry that I may have been exposed to the measles because I went on a fantasy ride called "It's a Small World". I wonder how these non-vaccinated children will feel about their parent's decision not to immunize them when they are adults?

As a parent of 3 children, a neonatal and pediatric nurse and a nursing faculty at a university where I teach pediatrics, community/public health, and health and wellness, I have never felt stronger about children receiving their vaccinations. I understand and agree with an immunocompromised child not being able to get vaccinated, that's where herd immunity comes into play. But not vaccinating your child due to a personal belief that the government should not have the right to dictate a proven practice that has eradicated deadly diseases such a small pox? That, I do not understand.

The chief medical correspond for CNN, Dr. Sanjay Gupta stated that vaccines have prevented 6 million deaths every year worldwide and have fundamentally changed modern medicine. Dr. Gupta also said that we are 100 times more likely to be struck by lightning than to have a serious allergic reaction to the vaccine that protects us against measles. Yet, parents are still choosing not to vaccinate their children.

Not immunizing children has an impact on the child and the family. Besides the discomfort, potential long term adverse affects and even death the child may face by getting a vaccine preventable disease, the child misses school; the child misses friends; the child misses socialization; they are even quarantined in their own homes isolated from their non-vaccinated siblings. In turn, parents miss work to care for their sick child. In 2012, a study of 310 working parents of children under 6 years old was done by University of Michigan's C.S. Mott Children's Hospital. The study looked at the impact of a child's illness on their families. While this study did not specifically focus on vaccine preventable diseases it emphasized the impact of having a sick child at home. Here are three of the key findings from the survey:

- 50 percent of the parents said that making other child-care arrangements was difficult.
- 33 percent said that taking time off from work to care for their sick child was difficult because doing so meant they lost pay or put their job at risk.
- 31 percent said that they didn't receive enough paid time off from work to care for their sick child.

Take chicken pox, a highly communicable disease with an incidence that has significantly decreased due to the varicella vaccination. A child with chicken pox maybe home for 10-14 days before all of the lesions are crusted over. Imagine the impact on the working family if the household has multiple non-vaccinated children who develop symptoms at different times!

A 2014 study from the University of Colorado School of Medicine stated every year,

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30,000 people on average die of vaccine preventable illnesses, almost all of them adults. Amy Parker is an adult whose health-nut parents did not vaccinate her. She contracted many communicable diseases as an adult, including vaccine preventable diseases such as measles, mumps, rubella, whooping cough, chickenpox and human papillomavirus. Thankfully, Amy survived all of her illnesses. Today, she has children of her own and her personal experience as a non-vaccinated adult is what prompts her to vaccinate her children and herself. Amy states she knows far more adults and children who suffer from complications of preventable childhood illnesses than those who suffer complications from vaccines. What is of utmost importance to Amy is if she did not vaccinate her children she would knowingly be exposing them to childhood illnesses, which she states is cruel.

In the midst of all the controversy that exists around vaccinations (autism, death with Gardasil, overwhelming the immune system) I, like Amy made the decision to have my children receive all of their vaccinations. I made this decision because I too was thinking about their future health status, their future as older children in school and eventually their future health as adults. It is our responsibility as health care providers and parents to protect our children, to make the right decisions for them when they cannot, to make decisions they will benefit from for their entire lives, to vaccinate them.

## Editorial

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# Medication Reconciliation in the Pediatric Emergency Room

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According to The Joint Commission, an accrediting organization certifying healthcare institutions in the United States, medication reconciliation is defined as the comparison between a patient's medication orders to those the patient was receiving prior to the hospital visit. Its purpose is to avoid medication errors such as omissions, duplications, dosing errors, or drug interactions. Medication reconciliation should be completed at every transition of care in which new medications are ordered or existing orders are rewritten when there are changes in setting, service, practitioner, or level of care.<sup>1</sup> In a pediatric emergency department setting, medication reconciliation is often challenging, owing to potential medication errors and discrepancies during handoffs at admission, transfer, and discharge of patients.<sup>2,3</sup> As a result, an Adverse Drug Event (ADE) defined as any preventable event that results in inappropriate medication use or harm to the patient while the medication is being handled by the health care professional, patient, or consumer can occur. The mean ADE rate in pediatrics is 2.3 to 11.2 per 100 pediatric admissions.<sup>1</sup> Therefore, the medication reconciliation process must be observed for safety, quality, and productiveness. This process encompasses five steps: (1) make a list of current home medications; (2) develop a list of medications that will be prescribed; (3) the two lists should then be compared; (4) clinical decisions should be made based on the comparison; and (5) this new list should be conveyed to health professional and patient.<sup>4</sup> A recent study conducted in outpatient pediatrics evaluated the implementation of an organized process to improve medication reconciliation. This trial reviewed over 2.7 million visits over a five year period and showed an improvement in documentation of medication reconciliation, satisfying the goal of patient safety.<sup>5</sup> The researchers defined patient safety as a means to reduce adverse drug events (ADE) and eliminate preventable harm. This trial used performance of MedRec measured over time from 2005 to 2010 to show that documentation improved consistently from a nadir of 0% in 2005 to 71% in 2010.<sup>5</sup> Some research has also been completed on quantifying discrepancies in admission medication history and reconciliation process at a pediatric institution. This prospective study identified a total of 309 discrepancies in 100 charts by pharmacists providing a potential to prevent significant ADEs.<sup>6</sup> Similarly, a larger scale review explored the occurrence of medication errors in multiple studies in pediatrics. Many studies consistently identified high rates of discrepancies ranging from 22 to 72.3% that occurred at all transitions of care.<sup>7</sup>

Few studies exist on the medication reconciliation in pediatric emergency departments. Further research is needed to confirm how implementing medication reconciliation may reduce medication errors and improve patient safety in the pediatric emergency department.<sup>8</sup> Guidelines establishing a standardized approach and model for medication reconciliation in the pediatric emergency department are necessary.

## DISCLOSURE

There are no conflicts of interest, or financial interest, in any product or service mentioned in the editorial, including grants, employment, gifts, patents, royalties, stocks, and honoraria to report.

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## Editorial

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# The Journal of Pediatrics and Neonatal Nursing: A Forum for Ideas, Innovation, and Illumination

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The inaugural issue of Pediatrics and Neonatal Nursing which debuted this past December was the culmination of months of dedication, innovative planning and collaborative effort of Openventio Publishers to serve the needs and well-being of infants, children, and adolescents. It is with great pleasure and privilege that I am honored to serve as Editor-In-Chief in what I hope will become a leading and longstanding resource for timely information, research, and education to benefit children of all ages and their healthcare providers.

Openventio Publishers through a broad scope of fields including all specialties and subspecialty areas of medicine and nursing demonstrates a commitment and vision to encourage and enhance research involvement of the clinical and basic science arena not to date seen by existing literature presentation. Its journals seek to create an open dialogue amongst clinicians and researchers of diverse backgrounds and levels of expertise from the established and funded to the novice and young investigator just beginning exploration to collectively contribute to contemporary levels of knowledge.

As to the background of your editor, my principal activity of today has been in the private sector of pediatric dentistry with emphasis on meeting the challenges of managing childhood dental fear and anxiety as well as those lacking cooperative potential. My career began as a fulltime educator, post-doctoral residency program director and behavioral researcher. Publications over the past three decades have focused on circumstances where conventional and mainstream communication strategies prove inadequate or inappropriate to help children cope with extensive and intrusive treatment. In my field, there is considerable interest directed at the development and provision of evidence based data for various pharmacological management approaches which demonstrate efficacy and safety in clinical settings. For the past twenty five years I have maintained an active albeit limited role in academic medicine and pediatric dentistry while teaching effective and safe use of pediatric sedation at three noted universities. Current energies involve conducting clinical research development and testing various sedation agents and combinations to best alleviate dental anxiety and phobia to best manage non-compliant child dental behavior.

These are exciting and dynamic times in pediatric healthcare. Imaginative and innovative approaches to enhance prevention, early diagnosis, and management of what was once regarded as devastatingly complex illnesses are underway in every subspecialty area. The journal enthusiastically encourages submission of manuscripts, critical and contemporary reviews of the literature, original prospective and retrospective investigations, topics related to access and obstacles to care, case reviews, editorial challenges and commentary.

We hope you will join and participate actively in the sharing and pursuit of excellence and illumination through the Pediatrics and Neonatal Nursing Open Journal. I look forward to your contributions. Through such conscientious efforts, we will be successful if we can serve as a canvas and platform for your energies and inspiration.

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## Research

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# Burden of Illness for Neural Tube Defects: Canadian Perspective

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## ABSTRACT

**Background:** Neural Tube Defects (NTDs) are serious birth defects of which Spina Bifida (SB) is the most common. This paper aims to provide an estimate of the burden of illness for patients with SB and their caregivers in Canada, to assess the benefit of primary prevention.

**Methods:** Individuals with NTDs were recruited through a hospital in Toronto. Using the clinic's database, individuals with SB and caregivers were screened to confirm eligibility. Data were collected using three types of questionnaires: sociodemographic, resource use and Quality of Life (QoL).

**Results:** Of 310 questionnaires sent, 66 individuals with SB and 66 caregivers responded. Most individuals with SB had a lesion in the lumbar area. More than half had presence of hydrocephalus. In the past 10 years, hospitalisation was the most used health care resource and most visited a urologist in the previous year. Caregivers reported various health conditions resulting from their role as carer. QoL scores were standardised using a United States general population. Results demonstrated that individuals with SB are lower on the physical component score but better on the mental component score.

**Conclusions:** The burden associated with individuals with SB in Canada is considerable. Our study highlights the need for primary prevention.

**KEYWORDS:** Burden of illness; Neural Tube Defects; Spina Bifida; Hydrocephalus; Resource use; Quality of Life; Canada.

**ABBREVIATIONS:** BMI: Body Mass Index; CI: Confidence Interval; EQ-5D: Euro QoL - 5 Dimensions; EQ-5DY: EuroQoL - 5 Dimensions Youth; GP: General Practitioner; HBKR: Holland Bloorview Kids Rehabilitation; HRQoL: Health-Related Quality of Life; ICU: Intensive Care Unit; MOS: Medical Outcomes Study; NTD: Neural Tube Defect; QoL: Quality of Life; SB: Spina Bifida; SD: Standard Deviation; SF-36: 36-Item Short Form; US: United States; VAS: Visual Analogue Scale.

## BACKGROUND

Neural Tube Defects (NTDs) are serious birth defects that involve incomplete development of the neural tube, which is the structure that becomes the spinal cord and the brain. There are several types of NTDs, all of which occur during early pregnancy, largely attribut-

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able to low levels of folate in women while conceiving.<sup>1</sup> Spina Bifida (SB) is used synonymously with NTDs. It actually falls within the spectrum of NTDs and this spectrum can range from mild with almost no problems to serious involving loss of bowel and bladder control, muscle paralysis, and loss of ability to sense urinary tract infection. NTDs can be further divided into three categories, ranging from mild to severe as listed: SB occulta; occult spinal dysraphism (lipomyelomeningocele); and SB cystica/aperta (myelomeningocele and meningocele).

Inconsistent coding of NTDs adds to the challenge of tracking the incidence. One recent analysis of the United States (US) NTD incidence rate (1991 to 2005) reported 17.96 cases of SB per 100,000 live births, whilst the anencephaly rate was recorded at 11.11 per 100,000 live births.<sup>2</sup> US incidence rates for SB range from 3 to 6 cases per 10,000 live births.<sup>3,4</sup> Infants with a NTD tend to have severe and life-long disabilities, and face the risk of psychosocial maladjustment.<sup>5</sup> Most are unable to function independently as adults, with common disabilities and medical problems including sight problems, dysfunction in the arms, epilepsy, bowel and bladder dysfunction. In addition to physical handicaps, SB causes significant neurocognitive and psychological morbidity in affected children as well as mental health burdens for their caregivers.<sup>5-7</sup>

Although most folate-dependent NTDs can be prevented by elevating folate levels in women wanting to become pregnant, most public health campaigns to date have been only partially successful in reducing the incidence.<sup>5</sup> A literature review of the economic burden of NTDs and prevention with folic acid showed that fortification of food with folic acid is a cost-effective method of reducing the burden of NTDs and therefore, their associated economic burden.<sup>8</sup>

However, the economic burden of SB remains significant. Total lifetime cost of a person with SB was estimated at \$635,763 (in 2001-2003 \$), with total direct costs of \$279,210, and indirect costs of \$356,553 (work productivity loss due to heightened morbidity and premature mortality).<sup>4</sup> Caregivers of children with SB worked an annual average of 7.5 to 11.3 hours less per week depending on the disability severity, which translated to lifetime costs of \$133,755 in 2002 \$.<sup>7</sup> Other studies have reported costs of US\$294,000 per infant.<sup>1</sup> In their working paper, Waitzman et al.<sup>9</sup> estimated the total lifetime cost of a SB patient to be US\$635,763, with total direct costs of US\$279,210, and indirect costs of US\$356,553 (work productivity loss due to heightened morbidity and premature mortality). A recent review of the social, psychological, and economic burdens experienced by people with SB and their caregivers showed that the average lifetime direct medical cost per person with SB ranges from US\$285,959 to US\$378,000 (in 2010 \$). This does not include lifetime direct non-medical costs (such as special education and development services) of US\$52,570 per person.<sup>5</sup>

Although data on the cost of SB to health care payers

are available, it is mainly limited to information from the US and there are no data available at present relating to the costs of SB in Canada. Data on the mental consequences of the disease are particularly scarce so quantifying the total burden remains a challenge. The main objective of this paper is to provide an estimate of the burden of illness for patients with SB and their caregivers in Canada.

## METHODS

### Participant Recruitment and Survey Procedures

The study was approved by the Holland Bloorview Kids Rehabilitation (HBKR) hospital research ethics board, and signed consent was obtained from all participants. Individuals with NTDs were recruited through the HBKR in Toronto and were eligible to participate if they met all the following criteria.

- 1) As judged by the investigator, have the cognitive ability to participate in the study or a patient representative who spends a minimum of two hours interacting with the patient in-person daily and is willing to participate as a proxy for the patient; and
- 2) Clinical diagnosis of SB (SB occulta or SB cystica/aperta) at any point during lifetime; and
- 3) Able to read and speak English or have a patient representative who is willing to assist the patient with completion of the survey forms; and
- 4) Willing and able to provide written informed consent prior to study entry or have a legal guardian who is able to provide consent on the patient's behalf prior to study entry.

For caregivers of individuals with SB, the participants had to meet all of the following criteria to be eligible.

- 1) At least 18 years of age; and
- 2) Able to read and speak English; and
- 3) Willing and able to provide written informed consent; and
- 4) Be an unpaid caregiver of a patient with SB who is also participating in the study (Note: caregiver must spend a minimum of two hours interacting with the patient in-person daily).

For caregivers, participants were excluded if they had a cognitive or other impairment (e.g., visual) that would interfere with them completing the study (assessed by the investigator).

If the patient had a cognitive or other impairment that would interfere with them completing the study, a patient representative could complete the measures for him or her. It was preferable that the patient representative was not also participating in the study as a caregiver.

### Database set-up

A database of all patients was created using the clinic's database and any new individual presenting with a diagnosis at

the clinic during the study. All potentially eligible individuals with SB and caregivers were sent a letter to inform them of the study and either telephoned or approached during a clinic visit to screen for interest and confirm eligibility.

Those who were part of the final study cohort were given all forms and surveys at the clinic visit to take home and complete or, where phone-screened, were sent a packet containing copies in the mail.

Parents/legal guardians of patients under the age of 18, or who did not seem cognitively able to complete the informed consent process, signed an informed consent form on the patient's behalf. For all child patients with SB under the age of 16, a patient representative completed the resource use questionnaire on the patient's behalf; however, the child could complete the appropriate Quality of Life (QoL) questionnaire(s) if the investigator and patient representative believed he or she was mentally capable.

### Questionnaires

Data were collected from patients and their caregivers using three types of questionnaires: self-developed sociodemographic questionnaire and resource use questionnaire; and three validated QoL questionnaires—EuroQol-5 dimensions (EQ-5D)/

EQ-5D Youth (EQ-5DY),<sup>10,11</sup> KIDSCREEN-10 (Child and Parent version for children), 36-Item Short Form (SF-36).<sup>12,13</sup>

Those with a diagnosis of SB responded to the first two questionnaires and the respective QoL questionnaire depending on their age (up to 12 years—EQ-5DY and KIDSCREEN-10; between 12 and 15 years—EQ-5D and KIDSCREEN-10; aged 16 and above—EQ-5D and SF-36).

Caregivers were asked to complete the first two questionnaires as well as the SF-36 and EQ-5D questionnaires to capture QoL. Participants could use their personal medical charts or personal diaries to assist with completion of the resource use and sociodemographic questionnaires. See Text Box 1 for more details on QoL questionnaires.

Within the sociodemographic questionnaire data were collected on: age; gender; race; education level; employment status; and living situation. In addition, data were collected on: body mass index (BMI; weight, height); type of lesion/severity of SB (occulta-hidden form, occult spinal dysraphism-lipomyelomeningocele, cystic myelomeningocele/meningomyelocele, meningocele); location of the lesion (cervical, thoracic, lumbar, sacrum, other); presence of hydrocephalus; type of treatment of hydrocephalus; level of mobility; and wheelchair use. Data on caregivers included information on the relationship with the patient.

#### Text Box 1

Three different validated instruments were used to assess Health-related Quality of Life (HRQoL) of patients with SB, including the version for children given the age range of these patients.

#### EQ-5D and EQ-5DY

The EQ-5D questionnaire is a generic, utility-based QoL instrument used for clinical and economic appraisal. The EQ-5D questionnaire has five dimensions including mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels: no problem, some problem, and severe problem. As no algorithm exists for the EQ-5D for Canada, the US algorithm was used. For the EQ-5DY no overall score can be calculated as no algorithm is yet available.

#### SF-36

The Medical Outcomes Study (MOS) SF-36 is a QoL instrument designed to assess generic health concepts relevant across age, disease, and treatment groups. It is aimed at both adults and adolescents aged 18 years and older. Nine different dimensions make up the SF-36: physical functioning (10 items); role-physical (4 items); bodily pain (2 items); general health (5 items); vitality (4 items); social functioning (2 items); role-emotional (3 items); mental health (5 items); and reported health transition (1 item).

#### KIDSCREEN-10

The KIDSCREEN-10 instruments assess children's and adolescents' subjective health and well-being. They were developed as self-report measures applicable for healthy and chronically ill children and adolescents aged from 8 to 18 years. They are available in child and adolescent as well as parent/proxy versions and have been translated and adapted for use in several languages. The KIDSCREEN-10 items use 5-point, Likert-type scales to assess either frequency (never-seldom-sometimes-often-always) or intensity (not at all-slightly-moderately-very-extremely). Rasch scores are computed for each dimension and for the overall score and are transformed into T-values with a mean of 50 and Standard Deviation (SD) of 10. The T scores refer to the mean values and SD from a representative sample of the European general population so that scores over (or under) 50 indicate better (or worse) HRQoL than the general population. As there is no general Canadian population data available, the European general population was used.

The resource use questionnaire for individuals with SB covered two periods: resource use in the last year and resource use in the last ten years. For caregivers, information on resource use only in the last year was collected. Caregivers were specifically asked to provide information on resource use that comes as a direct result of having to care for a person with SB. The following categories of data were included: health conditions; medical resource, such as hospital visits—out-patient, day-patient, in-patient/overnight stays, emergency room visits; visits to health care professionals; and medicines. In addition, patients' data included incontinence management; medical care and aid (new shunts, wheelchair, glasses, walkers, etc.); and changes to house/apartment due to SB (e.g., build wheelchair ramp). Other data included: productivity/work loss or sick leave from school; transportation to hospital and health care professionals; living arrangements; and special education received.

## Analysis

Baseline characteristics, QoL outcomes variables, variables on medical resource use and lost productivity were described for the entire study population and relevant subgroups of interest. For categorical variables, their distributions were described in terms of the number and proportion at each level of the variable; 95% Confidence Intervals (CIs) around these proportions were reported. Continuous variables were summarised in terms of the mean, Standard Deviation (SD), median, and range of values (minimum, maximum), with 95% CIs around the means being reported. For missing values, the number and percentage of missingness were reported for each variable.

The approach used to assess the association between patient groups and outcome variables depended on whether the latter was categorical (e.g., at least one overnight hospitalisation during the study period), or continuous (e.g., number of hospitalisations during the study period) variable. For categorical variables, the outcome was cross-tabulated by sub-groups of interest, to describe the proportion in each level having the outcome. For continuous variables, the distribution of the values of the outcome was described for sub-groups of interest.

## RESULTS

Of the 310 individuals with SB and their caregivers who were invited to participate in the study, 132 returned the questionnaires, including 66 individuals with SB and 66 caregivers.

### Participant Characteristics

The majority of individuals with SB participating in the survey were of white/Caucasian ethnicity (77%, n=51), were under 20 years old (98%, n=65) and over half were female (62%, n=41). Almost half were full-time students (n=30) and about 10% were in either full- or part-time employment or voluntary work.

Individuals with SB were classified by disease with most having lesion in the lumbar area (n=30), followed by other area (n=17), occulta/sacrum (n=14), thoracic (n=4), and cervical (n=1). They were also classified by disease severity, with those in the cervical or thoracic group classed as more severe and those in the occulta/sacrum group as less severe. The mean age for this group was 13 years old with patients in the thoracic and cervical group being 11.63 years and the lumbar group having the lowest average age of 9.48 years. More than half of the patients with SB had presence of hydrocephalus (53.03%). The mean age of patients with hydrocephalus was 10.31 years.

Co-morbidities included abnormal bladder function and incontinence for over 65% of patients; more than 50% reported urological abnormalities; almost half of patients had orthopaedic problems and latex allergy reaction; and around 20% had Chiari malformation, eye problems, paralysis or were wheelchair-bound. Those in the more severe, cervical/thoracic group had a trend toward higher number of urological complications with 80% (n=4) reporting abnormal bladder function and incontinence and 60% (n=3) reporting urological abnormalities.

Overall, abnormal bladder function was more common in younger patients (n=33, patients younger than 15 years of age), and particularly high in the '11 to 15 years' group (n=13). Urological abnormalities were also more prevalent in young and young adult patients (n=33, patients younger than 20 years of age) and was relatively higher in the '11 to 15 years' and the '15 to 20 years' groups (n=8).

Level of mobility for patients was limited with about a third of all patients reporting use of a wheelchair (n=19) or wearing braces on their feet or legs (n=18). Less than half (n=24) of patients could walk without assistance and three patients used a cane or other walking aid. Patients with hydrocephalus (53%, n=35) reported a higher rate of wheelchair use (46%, n=16) compared to those without and use of foot/leg braces was almost equal in patients with (26%, n=9) and without hydrocephalus (29%, n=10). Those without hydrocephalus were more likely to walk without assistance (55%) compared to patients with this condition (20%).

The majority of caregivers were female (n=64), most were the mother of a person with SB (n=62) and most lived with the person with SB (n=59) and a partner/spouse (n=38) or other member of the family who was not the patient (n=32). Over half (n=34) had a college degree and nearly a quarter (n=15) had studied at postgraduate level, but only 42% (n=28) were in full-time employment and those working part time (n=17) worked a mean of 23 hours per week and reported their role as care provider as the reason. Caregivers reported a variety of health conditions including lower back pain, joint problems, anxiety, high blood pressure and depression. In all, 76% (n=50) of caregivers reported that their health problems were the result of their role as carer for patients with SB.

## Resource Use

### Caregivers

Data on resource use were reported both for the period of the last year (all) and the most recent 10 years (individuals with SB only). Of the 66 caregivers in the study, during the past year 16 had visited a General Practitioner (GP) in office as a result of their care for the person with SB, six had visited another hospital specialist, five had visited a community physiotherapist or occupational therapists and four the orthopaedist. Among caregivers with at least one use of health care resources, there were six visits to outpatient services (hospital appointments), two day-patient visits and two emergency room visits.

### Individuals with SB: previous year

During the year prior to survey administration, the majority of individuals with SB visited an urologist (71%, n=47), GP (66%, n=44) and an orthopaedist (64%, n=42). Among individuals with at least one visit, the most frequent were the outpatient appointments (64%, n=42), in-patient stay (30%, n=20), day-patient visit (29%, n=19), in-patient surgery (27%, n=18) and emergency room visit (26%, n=17). The mean length of in-patient stay per person with at least one visit was 7.15 days in a normal ward, and six days in the Intensive Care Unit (ICU). The most used items by individuals with SB during the last year were incontinence pads and urinary catheters (68%, n=45) or bowel incontinence products (45%, n=30).

On average, individuals with SB were driven around 52 times by a caregiver or other person, who was not paid for the service, to health care services. They used transport services to go to the hospital, doctor, specialist or rehabilitation visit around nine times a year and only once drove themselves to health care services. Some (12%, n=8) had to make changes to their house/

apartment because of their condition, including bathroom renovations, installing ramp and railing, wheel in shower, grab bar in shower and new bed to improve function.

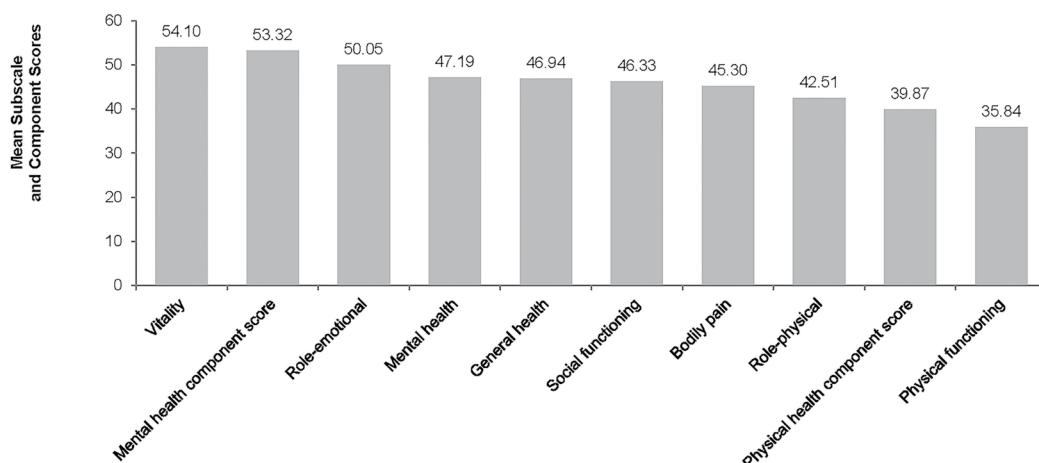
### Individuals with SB: previous 10 years

In the past 10 years, hospitalisation was the most used health care resource (77%, n=51), with the overall mean length of rehabilitation stay being 135.50 days, and the mean length of stay per person being 32.79 days. Most individuals with SB resided full time in a private home, either with parents or a partner in the previous 10 years. Other resource use included 31 individuals with SB who used physical therapy services, 26 used orthopaedic shoes and 25 reported using a wheelchair. Among those with at least one health care resource use, there were 20.25 additional procedures, events or physician visits in the past 10 years.

In terms of productivity lost, in the past year, individuals with SB who attended a school had a mean of 15.17 sick days because of their condition, whereas those working full time only had a mean of two sick days.

### Adult QoL Questionnaires for Individuals with SB

The results from the SF-36 questionnaire are presented in Figure 1. The lowest scores within the physical and mental components were physical function (35.84) and social function (46.33). Overall, the mean physical scales/component scores indicated worse than the US population but the mean mental scales/component scores indicated better than the US population. The pair-wise correlation analysis showed that there is an inverse correlation between all SF-36 subscales and the age; however, correlation coefficient was not statistically significant (see Table 1).



Norm-based scoring has been applied here as general population norms provide a much better basis for comparisons across scales. In norm-based scoring, each scale was scored to have same average (50) and the same standard deviation (10 points) and differences in scale scores much more clearly reflect the impact of the disease, in this study the impact of neural tube defects.

Figure 1: Patients: SF-36 Subscale and Component Scores

	N	Patient's Age r	p
Physical functioning	14	-0.33620	0.2399
Role-physical	14	-0.09106	0.7569
Bodily pain	14	-0.31146	0.2784
General health	14	0.02322	0.9372
Vitality	14	-0.48156	0.0812
Social functioning	14	-0.19705	0.4995
Role-emotional	14	-0.15745	0.5909
Mental health	14	-0.12430	0.6720
Physical health component score	14	-0.26119	0.3671
Mental health component score	14	-0.08917	0.7618

Correlation coefficients (r) represent the linear relationship between two variables and can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A value of 0.00 represents a lack of correlation.\*If each p-value is lower than 0.05, then the correlation coefficient is statistically significant.

**Table 1:** Pair-wise Correlation of Patient's SF-36 Subscale and Component Score and Patient's Age

EQ-5D were reported by 93% (n=31) of responders (see Table 2). The mean EQ-5D utility score was 0.64 and mean EQ-5D Visual Analogue Scale (VAS) was 78.93. There were 3% and 7% of patients who reached the ceiling of utility and VAS scores, respectively. The majority of patients reported having 'some' (n=13) or 'lots of' (n=7) problems with mobility. There was no significant correlation between the EQ-5D scores and utilities and the patients' age (see Table 3). Pain and discomfort subscales had a statistically significant and positive correlation with patients' age (p=0.02, correlation co-efficient r=0.435).

#### Child QoL Questionnaires for Individuals with SB

EQ-5DY and KIDSCREEN-10 reported by over 90% of responders (see Table 4). The mean EQ-5DY utility score was 0.50 and mean EQ-5DY VAS was 74.21. There were 14% and 5% of patients who reached the ceiling of utility and VAS scores, respectively and 10% of patients reached the flooring of utility score. Some patients reported having lots of problems with mobility (n=7) and some problems with usual activities (n=10).

(N=29)	N	Mean	SD	Median	Min	Max	% Ceiling	% Floor	N (%) Missing
	27						-	-	2 (6.90)
Mobility		2.00	0.73	2.00	1.00	3.00	-	-	
Self care		1.44	0.58	1.00	1.00	3.00	-	-	
Usual activities		1.59	0.50	2.00	1.00	2.00	-	-	
Pain/discomfort		1.67	0.62	2.00	1.00	3.00	-	-	
Anxiety/discomfort		1.30	0.47	1.00	1.00	2.00	-	-	
EQ-5D utility		0.64	0.31	0.79	0.15	1.00	3.45	0.00	
EQ-5D VAS		78.93	16.20	85.00	30.00	100.00	6.90	0.00	

Average EQ-5D utility in general population is 87.3. Average EQ-5D VAS score in general population is 80.9. (16)

**Table 2:** EQ-5D Scores and Utilities of Patients

	N	Patients' Age R	p
Mobility	27	0.00000	1.0000
Self care	27	-0.26595	0.1800
Usual activities	27	0.05600	0.7814
Pain/discomfort	27	0.43459	0.0235*
Anxiety/discomfort	27	0.25918	0.1917
EQ-5D utility	27	-0.18633	0.3521
EQ-5D VAS	27	-0.10612	0.5983

Correlation coefficients (r) represent the linear relationship between two variables and can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A value of 0.00 represents a lack of correlation. \*If each p-value is lower than 0.05, then the correlation coefficient is statistically significant.

**Table 3:** Pair-wise Correlation of Patients' EQ-5D and Patients' Age

The pair-wise correlation analysis showed that there is inverse correlation between self-care, anxiety/discomfort subscales of EQ-5DY, as well as EQ-5DY utility scope and VAS, and patients' age; however, correlation coefficient was not statistically significant (see Table 5).

For KIDSCREEN-10, 30 children and adolescents, and 29 parents completed the KIDSCREEN10 Health-related Quality of Life (HRQoL) questionnaire and had a mean score of 47.10 and 43.94 respectively.

#### Caregiver QoL Questionnaires

Overall, the mean physical scales/component scores indicated worse than the US population, and the mean mental scales/component scores indicated better than the US population (see Figure 2). Physical health component scores exhibited a trend towards higher values in caregivers of individuals with presence of hydrocephalus (50.36) compared to those without (49.25) as were the mental health component scores, 46.56 and 43.81 respectively.

As shown in Figure 3, physical health component scores were lowest in caregivers of patients with cervical or thoracic disease severity (44.27) compared to occulta/sacrum (49.00) and lumbar (50.70). Caregivers of patients with occulta/sacrum disease severity had the lowest mental health component score (40.54), compared to patients with cervical or thoracic (44.18) and lumbar disease severity (47.46). The pair-wise correlation analysis reported in Table 6 showed statistically significant inverse correlation between bodily pain and physical health component scores of caregiver SF-36 subscales and patients' age ( $p=0.03$ , correlation coefficient  $r=-0.43$  and  $p=0.04$  correlation co-efficient  $r=-0.032$  respectively).

The mean EQ-5D utility and VAS scores for caregivers were 0.88 and 77.67, respectively (see Table 7). Forty-seven percent of caregivers reached the ceiling of utility and 8% VAS scores. The summary of the EQ-5D utility (0.89) and VAS (78.86) scores for caregivers of patients with SB with presence of hydrocephalus were slightly higher (see Figure 4), compared to those who were caring for patients without presence of hydrocephalus (0.86 and 76.18, respectively). The lowest EQ-5D

(N=21)	N	Mean	SD	Median	Min	Max	% Ceiling	% Floor	N (%) Missing
	<b>19</b>								<b>2(9.52)</b>
Mobility		2.05	0.85	2.00	1.00	3.00	-	-	
Self care		1.95	0.78	2.00	1.00	3.00	-	-	
Usual activities		1.95	0.71	2.00	1.00	3.00	-	-	
Pain/ discomfort		1.74	0.73	2.00	1.00	3.00	-	-	
Anxiety/ discomfort		1.68	0.75	2.00	1.00	3.00	-	-	
EQ-5DY utility*		0.50	0.42	0.70	-0.21	1.00	14.29	9.52	
EQ-5DY VAS		74.21	20.02	80.00	25.00	100.00	4.76	0.00	

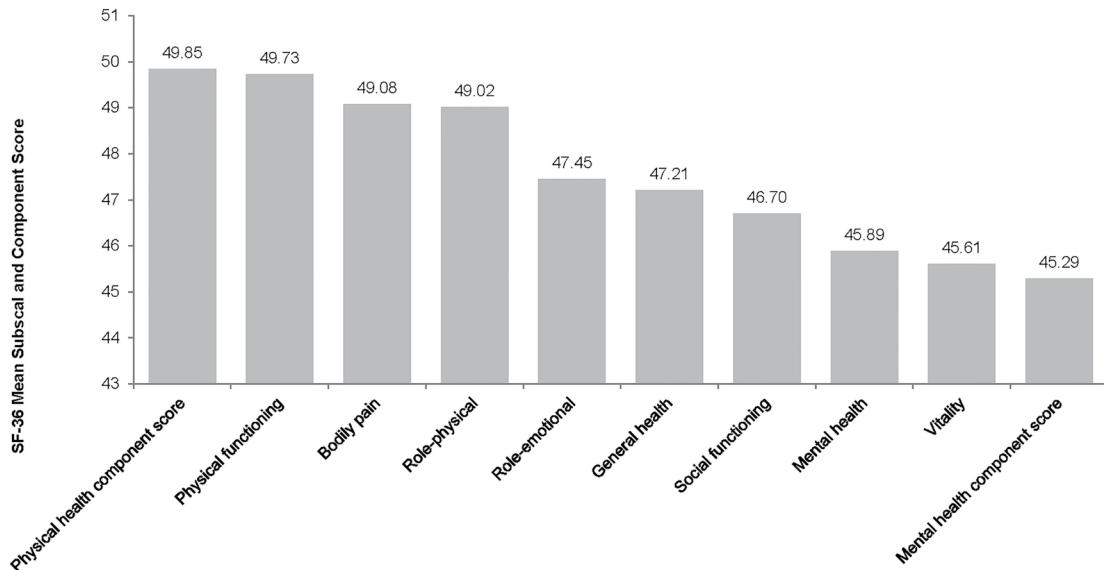
\* No algorithm for the EQ-5DY exists; the EQ-5D algorithm for adults was used instead.

**Table 4:** EQ-5DY Scores and Utilities of Patients

	N	Patients' Age r	p
Mobility	19	0.03983	0.8714
Self care	19	-0.00902	0.9708
Usual activities	19	0.06588	0.7887
Pain/discomfort	19	0.20724	0.3946
Anxiety/discomfort	19	-0.19912	0.4138
EQ-5D utility	19	-0.12258	0.6171
EQ-5D VAS	19	-0.37932	0.1092

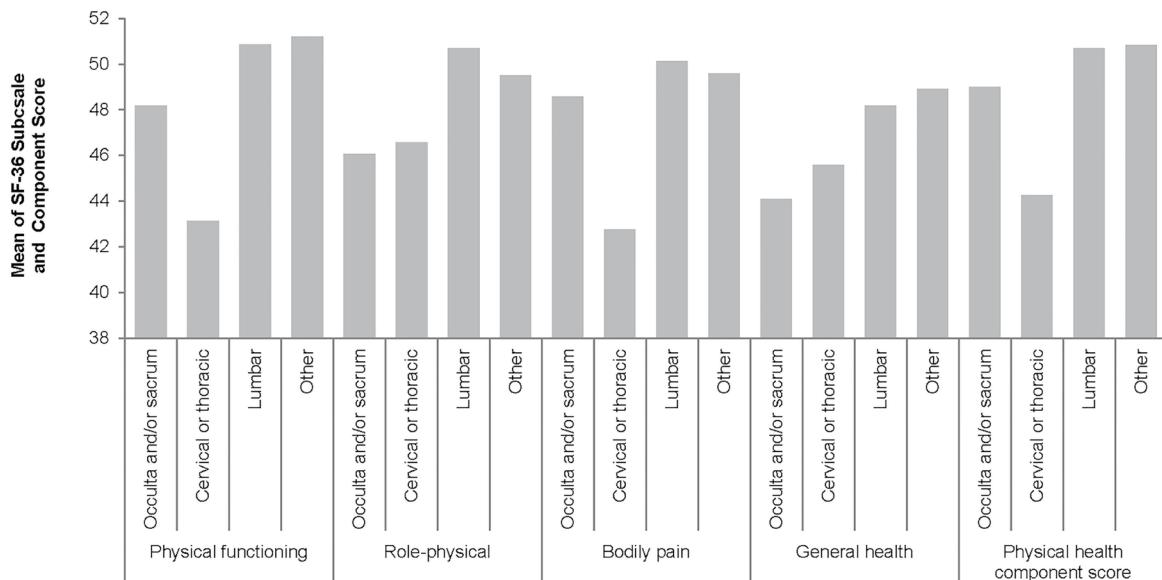
Correlation coefficients (r) represent the linear relationship between two variables and can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A value of 0.00 represents a lack of correlation. \*If each p-value is lower than 0.05, then the correlation coefficient is statistically significant.

**Table 5:** Pair-wise Correlation of Patients' EQ-5DY and Patients' Age



**Note:** Each scale was scored to have the same average (50) and the same standard deviation (10 points). With norm-based scoring, differences in scale scores more clearly reflect the impact of the disease

Figure 2: SF-36 Subscale and Component Score of Caregivers



**Note:** Each scale was scored to have the same average (50) and the same standard deviation (100 points). With norm-based scoring, differences in scale scores more clearly reflect the impact of the disease.

Figure 3: SF-36 Physical Subscale and Component Score of Caregivers-By Disease Severity

utility (71.33) and VAS (0.82) scores were in caregivers of individuals with occult/sacrum disease severity (Figure 5). As reported in Table 8, the pair-wise correlation analysis showed statistically significant correlation between mobility of caregiver EQ-5D component score and patients' age ( $p=0.017$ , correlation co-efficient  $r=0.29$ ). There was a statistically significant correlation between the individuals' and caregivers' mental health component scores but correlation between the patients' and caregiv-

ers' physical health component scores, as well as EQ-5D utility and VAS, were not statically significant.

## DISCUSSION

The main objective of this paper was to highlight the overall burden of illness of NTDs in Canada, of which SB is the most common. Previous research has suggested that most

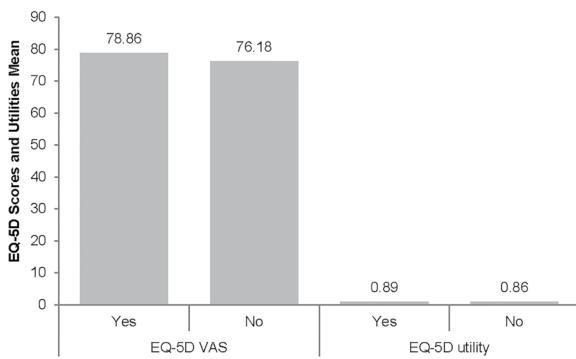
	N	Patients' Age r	p
Physical functioning	65	-0.20985	0.0934
Role-physical	65	-0.10789	0.3923
Bodily pain	65	-0.26498	0.0329*
General health	65	-0.19807	0.1137
Vitality	65	0.09457	0.4536
Social functioning	65	0.04127	0.7441
Role-emotional	65	-0.00570	0.9640
Mental health	65	-0.03266	0.7962
Physical health component score	65	-0.25348	0.0416*
Mental health component score	65	0.07506	0.5523

Correlation coefficients (r) represent the linear relationship between two variables and can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A value of 0.00 represents a lack of correlation. \*If each p-value is lower than 0.05, then the correlation coefficient is statistically significant.

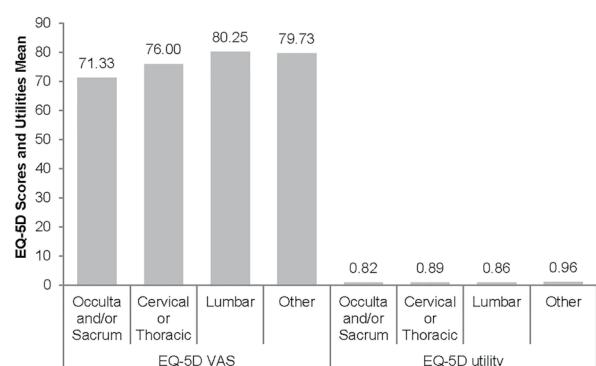
**Table 6:** Pair-wise Correlation of Caregivers' SF-36 Subscale and Component Score and Patients' Age

(N=66)	N	Mean	SD	Median	Min	Max	% Ceiling	% Floor	N (%) Missing
	<b>64</b>								<b>2 (3.03)</b>
Mobility		1.20	0.41	1.00	1.00	2.00	-	-	
Self care		1.05	0.21	1.00	1.00	2.00	-	-	
Usual activities		1.23	0.46	1.00	1.00	3.00	-	-	
Pain/discomfort		1.52	0.64	1.00	1.00	3.00	-	-	
Anxiety/discomfort		1.34	0.54	1.00	1.00	3.00	-	-	
EQ-5D utility		0.88	0.22	0.99	0.18	1.00	46.97	0.00	
	<b>63</b>								<b>3 (4.55)</b>
EQ-5D VAS		77.67	14.90	80.00	35.00	100.00	7.58	0.00	

**Table 7:** EQ-5D Scores and Utilities of Caregiver



**Figure 4:** EQ-5D Scores and Utilities of Caregivers—By Presence of Hydrocephalus



**Figure 5:** EQ-5D Scores and Utilities of Caregivers—By Disease Severity

	N	Patients' Age r	p
Mobility	64	0.29572	0.0177*
Self care	64	0.12025	0.3439
Usual activities	64	0.02868	0.8220
Pain/discomfort	64	0.22674	0.0716
Anxiety/discomfort	64	0.15642	0.2171
EQ-5D utility	64	-0.17455	0.1677
EQ-5D VAS	63	-0.14224	0.2661

Correlation coefficients (r) represent the linear relationship between two variables and can range from -1.00 to +1.00. The value of -1.00 represents a perfect negative correlation while a value of +1.00 represents a perfect positive correlation. A value of 0.00 represents a lack of correlation. \*If each p-value is lower than 0.05, then the correlation coefficient is statistically significant.

**Table 8:** Pair-wise Correlation of Caregivers' EQ-5D and Patients' Age

individuals with SB are unable to function independently as adults due to life-long disabilities and medical problems, such as bladder and bowel dysfunction. In addition to physical handicaps, SB has been shown to cause significant neurocognitive and psychological morbidity in both affected children and their caregivers.<sup>6,7</sup>

When assessing the QoL, subscales and scores were standardised using a US general population to provide a better basis for comparison across scales. Results of the QoL analysis demonstrated that individuals with SB are lower on the physical component score compared to the US population, but better on the mental component score. Analysis of QoL among caregivers showed that the average mental component score was slightly lower in contrast to the physical component score, which was much worse than the US population. When comparing caregivers for those with and without presence of hydrocephalus, both physical and mental component scores were higher for caregivers of individuals with hydrocephalus, indicating a likely more severe nature and, as a result, burden for those with hydrocephalus. Subgroup analyses based on location of the lesion confirmed this assertion.

Our results demonstrate a substantial use of health care resources by individuals with SB and the need for assistance in accessing those resources due to mobility problems. Persons with SB sought care in all of the settings—beginning with frequent visits to the GP office, visits to specialists (urologists and orthopaedists, in particular) and relatively frequent and prolonged hospitalisations. Patients frequently used assistive devices such as wheelchairs, or orthopaedic shoes, and incontinence pads and urinary catheters were the most used items in the last year.

A literature review of cost of illness studies reported that the lifetime direct medical cost for patients with NTDs (including SB) is substantial, with the majority of cost being for in-patient care for treatment at initial diagnosis in childhood, and for comorbidities in adult life.<sup>8</sup> Many studies have shown that achieving adequate folate levels around the time of conception

has been beneficial in decreasing the potential risk of SB occurrence by 60% to 80%.<sup>14,15</sup>

Our results indicate that the majority of patients with SB saw a physician or a specialist in the prior year and that they visited health care professionals multiple times per year. They also had frequent hospitalisations with an extended length of stay. Consistent with our findings, a study of secondary care data in the US showed that, when compared with the general population, persons with SB who were hospitalised in 2004 had a significantly greater number of hospitalisations and number of hospitalisations associated with SB-sensitive conditions.<sup>16</sup>

Another US study evaluated the use of assistive technologies among patients with SB.<sup>17</sup> Fifty-seven percent used wheelchairs, 35% used braces, and 23% used walking aids. In our study, although only around one third reported using a wheelchair, nearly a third wore braces on their feet or legs.

There were some limitations to this study. Response and selection bias are typically present in studies using survey methodology. In this study around a third of the eligible population participated. Those with greater mobility and in better health were more likely to be recruited and participate in the study due to the recruitment methodology. This indicates that the actual burden of the condition is underestimated, so estimates should be treated as conservative. Lack of generalisability due to a low number of patients should also be acknowledged. Finally, self-reported data on resource use are not considered as gold standard; patients tend to over-report more serious events (e.g., hospitalisations) and under-report those that they consider common or every day (e.g., scheduled visits). In addition, the reliability of data from the previous 10 years may not be high; however, the study design attempted to minimise the limitations associated with recall by allowing the use of medical or other records and by asking questions on only serious health use events.

Despite these limitations, the study has two considerable strengths. The sample size, though relatively small, is greater than in other studies reporting data directly from individuals with SB and includes data on both child and adult individuals. The resource use questionnaire provided a very detailed description of health care use both over the short and long term; thus, the results provide a very complete picture of the burden of SB.<sup>18</sup>

## CONCLUSION

Findings from this study confirm that the burden associated with patients with SB in Canada is considerable. The physical component of QoL scores is lower compared to the mental component in patients with SB. In caregivers, both physical and mental component scores are higher for those with patients with hydrocephalus. Resource use is high in this population, with frequent GP and urologist visits. The burden is also high for patients

who have to take days off school due to their condition. Overall, our study adds to a growing body of research highlighting the need for primary prevention and additional measures beyond health care campaigns.

#### ACKNOWLEDGEMENTS

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# Reflexion about Pediatrics, Anesthesia and Education in Pediatric Anesthesia in Colombia and South America

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### ABSTRACT

Latin America is a region with large changes in the last decade with the purpose of improving its political, economic, social and cultural situation. It must face a series of challenges to improve safety, health and education for people. This situation is no different in medical education and the way in which health systems operate in the region. The aim of this article is to reflect the global situation from the pediatric anesthesia perspective and to analyze important aspects as health, infant mortality, poverty and education opportunities in Latin America. After a thorough investigation to collect some statistics from this region, different web pages and official government websites were consulted to get a diagnosis of the situation of pediatrics and pediatric anesthesia in Colombia and South America; its challenges and the current projects from different countries with the goal to improve education and ensure better living conditions for children in this region of the world.

**KEYWORDS:** Children; Mortality; Education; Anesthesia; South America.

### INTRODUCTION

Talking about pediatric anesthesia and education in Latin America implies analyzing the global situation of the region. The goal of this reflection is to describe the situation of pediatric anesthesia in Colombia and South America; to explain the current difficulties of the region and the challenges that we have to face to improve education in this field.

### Background

Colombia is located in the northwest tip of South America. It has about 48 millions of inhabitants in an area of over seven hundred thousand square miles.<sup>1</sup>

Nations in South America and The Caribbean have specific goals in order to improve the quality of life of the population (*the millennium goals*) those goals are: to reduce child mortality, to reduce hunger and poverty, to reach gender equality, and to improve access to education and to protect the environment and natural resources.<sup>2</sup>

Colombia has about 12 million of children under the age of 15 years, (25% of country population). In 2013, Colombia had almost 600.000 births, with a birth rate of 19 for 1.000 people.<sup>3,4</sup> This rate is lower than the average of South America, but it is higher than in North America and Europe.<sup>5</sup> (Figure 1)

The birth rate in the world has a tendency to decrease as the timeline advances. The same tendency occurs with child mortality, which has changed dramatically by regions in the

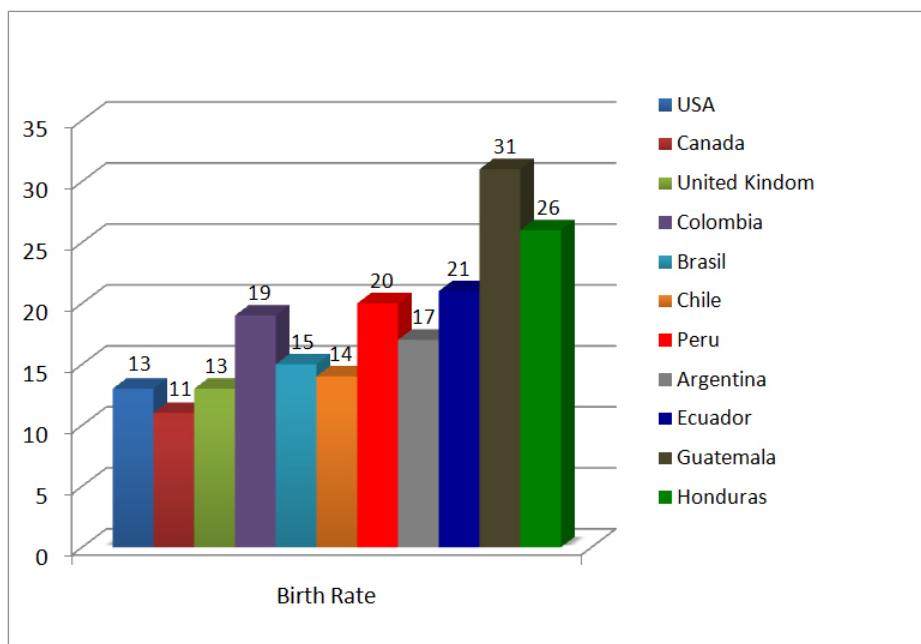


Figure 1: Birth rate of different countries in the world. Number per 1.000 inhabitants

Source: modified from <http://www.indexmundi.com/g/r.aspx?v=254>

last decade. Children mortality has declined in the last ten years by different reasons<sup>6</sup>: actions to improve mother's health, prenatal care programs and better conditions for mothers have been crucial to diminish mortality in babies under 1 year. But also, social policies as contraception programs in adolescents, massive vaccination in children and vulnerable population, better possibilities to attend school and the improvement of life conditions in the rural area, are some of the most important strategies to reduce mortality in children. However, the children mortality in Colombia is still high and the main causes of death in children still are malnutrition (13% of cases),<sup>6</sup> perinatal afflictions, respiratory infections and accidents. This statistics are different among regions. Main cities (Bogota, Medellin) have the lowest mortality rate in the country (10-12/100.000) where people can have access to integral healthcare services and better opportunities to get education, but rural areas as Vaupés, Guainía, Choco and La Guajira have mortality rate as high as Africa (22-49/100.000)<sup>7,8,9</sup> where population have the highest levels of poverty and forced displacement by violence and the access to health care is scarce.<sup>10</sup> Poverty is directly related to mortality as well. Colombia has a poverty index of 34% and 10% of the population live in extreme poverty.<sup>11</sup> However, the problem is not only the poverty itself as the bad distribution of the wealth in the region.<sup>12</sup>

The mortality rate in children by regions in the world is showed in figure 2.<sup>13</sup>

#### The situation of pediatrics and anesthesia in the region

Colombia has 3.180 anesthesiologists to attend 48 mil-

lion of people with 12 million of children.<sup>3,14,15</sup> Currently, there are 24 anesthesia programs in all the country that graduate about 120 new anesthesiologists per year. The time dedicated to pediatric anesthesia in three years of residence is between 2 to 5 months, which is not enough time to acquire a deep knowledge and skills in pediatrics.<sup>16</sup> So far there are not pediatric anesthesia fellowships in Colombia.

This outlook is not different from other South American countries. Table 1 describes the number of anesthesiologists available in each country and its ratio with the number of inhabitants.

Although the number of anesthesiologist by inhabitants depends of every country, it is considered as a good relation to have about 1 anesthesiologist by 5.000 to 10.000 inhabitants,<sup>15</sup> so there is a deficit of human resource in anesthesiology in the region.

The hospital infrastructure is insufficient as well. Colombia has only 11 pediatric hospitals in all territory. Many of them are not exclusively dedicated to pediatric patients, so most of the pediatric population receive healthcare in general hospitals.

The number of pediatric beds in Colombia is 10.642 with a ratio of about 1 bed per 1.1000 inhabitants in Colombia; although there is not an ideal number of beds, the World Health Organization recommends a number of 3-5 beds per 1.000 inhabitants.<sup>18</sup>

## Under-five mortality rate by region, 1970-2011 (per 1,000 live births)

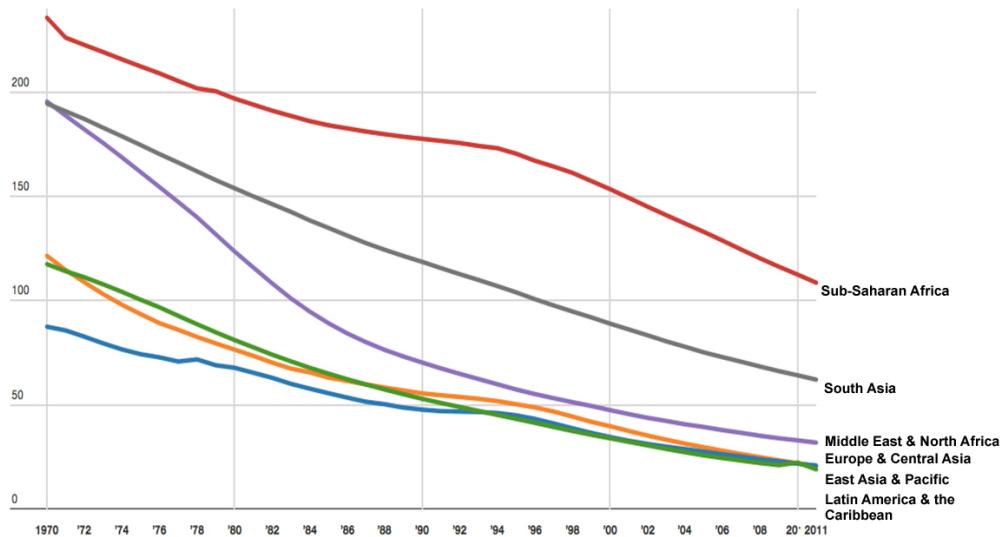


Figure 2: Children mortality rate in children under five years by regions in the world.

Source: <http://blogs.worldbank.org/opendata/node/544>

Country	Population	Number anesthesiologists	Ratio Anesthesiologist/inhabitant
Brazil	194.933.000	12.000	1/16.000
Mexico	120.000.000	12.000	1/10.000
Colombia	48.000.000	3.180	1/15.000
Argentina	40.900.000	3.800	1/10.000
Peru	29.277.736	600 (1995)	-
Venezuela	29.277.000	3.226	1/9.000
Chile	17.248.000	1.200	1/14.000
USA	300.000.000	35.000	1/8.500
United Kingdom	63.000.000	10.000	1/6.300

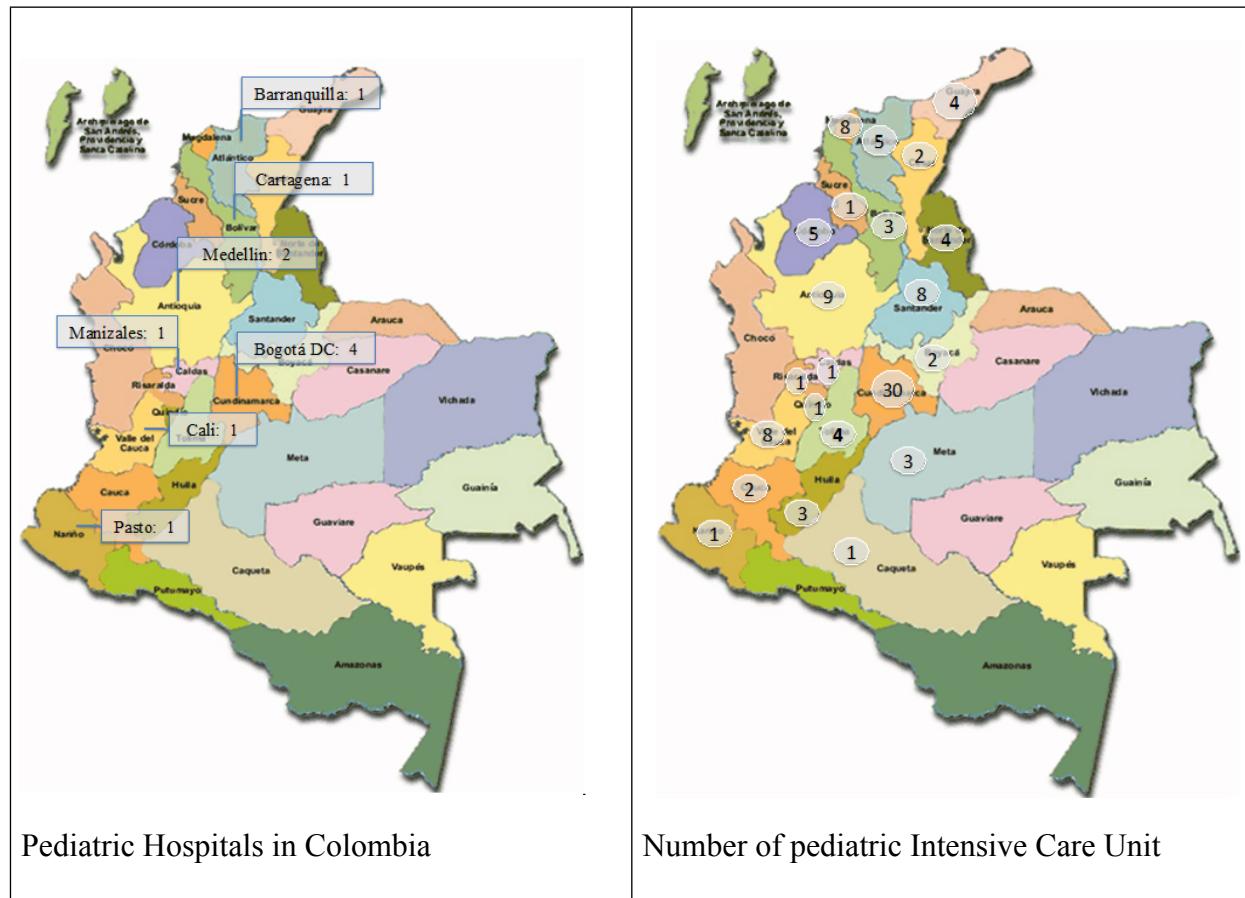
Table 1: Survey to members of anesthesiology societies in South America. Dates modified from Calabrese D. [clasa-anestesia.org](http://clasa-anestesia.org)<sup>17</sup>

Again, the problem is not only about the number as the geographical distribution, because there are regions in the country where pediatric hospitals are not available. (Figure 3)

A similar situation occurs with Pediatric Intensive Care Units (PICUs) that are available in the country to attend critically ill children. There are 115 PICUs with 870 beds. It means a ratio of 1 bed per 14.000 children; and it is even worse in some countries of South America and the Caribbean, where the ratio is 1 PICU bed per 40.000 inhabitants.<sup>19</sup> The difference is huge compared to some high-income countries: United States has 21.000 PICU beds,<sup>20</sup> (1 PICU bed per 3700 children) or Germany, 1 PICU per 4.000 children.<sup>21,22</sup>

Again, the human resource is limited in Colombia because only 49% of these units have a pediatric intensivist and it could be one of the reasons why the mortality in PICUs in Colombia and Latin America is higher than other regions in the world (13% in Latin America vs. 5% in Europe).<sup>19</sup> The distribution of these PICUs is focused in the central area of the country and some regions lack of PICU beds. (Figure 3)

In summary, Colombia and Latina America has a real deficit of human resources, hospital infrastructure and technology, but the most serious problem, is the bad distribution of health resources by regions.



**Figure 3:** Distribution of the pediatric hospitals in the country (right) and number of PICU in Colombia (left). Source: The author.

Pediatric Anesthesia

Colombia has about 80 anesthesiologists who have dedicated their professional life to work with children in pediatric hospitals. Also, there are six anesthesiologists trained in pediatric anesthesia by The Colombian Society of Anesthesia (2003 to 2009); and there are about twenty anesthesiologists in Colombia who have done a fellowship abroad. In summary there is about one hundred pediatric anesthesiologists to attend children in all the country.

The possibilities to apply for a pediatric anesthesia fellowship in Latin America are limited. There are five programs in Latin America: Mexico, Venezuela, Argentina, Costa Rica and a special training program in Chile accredited by the World Federation of Societies of Anesthesiology (WFSA).<sup>23,24</sup> (Figure 4)

In synthesis, Colombia and South America have a deficit of human resources in pediatric anesthesia. It is difficult and expensive to bring them from abroad and although it is a challenge to create new fellowships programs in the region, some countries are currently working to get their own programs. However it is essential to have specialized staff due to the consider-

able number of children in Latin America (about 117 million of children),<sup>25</sup> the complexity of pathologies in childhood and to improve safety in children's health care. Besides, to guarantee skills and knowledge in pediatrics patients, anesthesiologists should receive an additional training to decrease perioperative complications.<sup>26,27</sup>

## The future direction of pediatric anesthesia in the region

There are some projects that anesthesiology societies in South America have developed to improve knowledge, safety and training in pediatric anesthesia. The most important is the program of continued education, which integrates a number of local meetings, workshops and national congress with the cooperation of different countries, publications in local and international journals, and the new editions of books of pediatric anesthesia in Spanish made with the cooperation of American authors who have excelled in this field.<sup>28</sup> Also there is a virtual platform to extend education programs through e-learning module created by Colombian Society of Anesthesiology which is available for South America and the Caribbean.<sup>29</sup>

And finally, Colombia, Chile and Brazil are working



**Figure 4:** Countries that currently have fellowship programs in pediatric anesthesia in Latin America and the number of fellowships available by programs in each country. Source: The author.

to create their own fellowships in pediatric anesthesia to train anesthesiologists from the region in pediatric hospitals and teach them the basic principles of good practice, safety and promote investigation in the area of pediatrics.<sup>16,30</sup>

## CONCLUSION

Colombia and South America are facing a lot of challenges, but the main change is changing minds. This goal is only possible through education.

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## ETHICAL ISSUES

This paper does not compromise any institution or people. It has made with general information available for general audience published by different entities and government official websites in the region.

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## Review

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# Nursing Care of Infants and Children with Bronchiolitis

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## ABSTRACT

Bronchiolitis is the most common cause of lower respiratory infection in the first year of life. It is a leading cause of acute illness and hospitalization for infants and young children worldwide. Previous studies have demonstrated that at least 1% of children younger than 24 months of age are hospitalized for bronchiolitis. These hospitalizations have been found to consume a significant amount of health care resources. The primary treatment of bronchiolitis remains largely supportive with administration of fluids and supplementary oxygen, observation and mechanical ventilation if needed. Other types of treatment remain controversial. Successful treatment of this diagnosis requires coordination of care of a multidisciplinary team. Pediatric nurses and advanced practice pediatric nurses in both primary and acute care clinical settings can play a major role in educating other health care professionals on the use of Evidence-based practice and why it is important to decrease costs and improve patients' outcome by changing the traditional and habitual use of diagnostic and therapeutic options that are no longer recommended by the most recent guidelines. The purpose of this review was to identify the best evidence available for the updated management of infants and children with bronchiolitis. This updated simplified management of infants with bronchiolitis would result in not only decreasing the cost of care but also result in a better outcome as mentioned in guidelines according to the recent literature.

**KEYWORDS:** Bronchiolitis; Respiratory syncytial virus; Bronchiolitis management; Nursing care.

**ABBREVIATIONS:** RSV: Respiratory Syncytial Virus; LOS: Length of hospital stay; RR: Respiratory Rate; NG: Nasogastric; ADH: Antidiuretic Hormone; HS: Hypertonic Saline; CPT: Chest physiotherapy; ED: Emergency Department; HFNC: Humidified High-Flow Nasal Cannula; CPAP: Continuous Positive Airway Pressure; BPD: Broncho-pulmonary dysplasia; CF: Cystic Fibrosis.

## EPIDEMIOLOGY

Respiratory Syncytial Virus (RSV) accounts for 60-85% of cases. Rhinovirus, human metapneumovirus,<sup>1</sup> adenovirus, parainfluenza, influenza, paramyxovirus (hMPV), Bocavirus or co-infection occur in 10-30% of cases.<sup>2</sup> Associated bacterial infection was observed in 10% of cases.<sup>2,4</sup> The incubation period is approximately 4 days, but the virus can be shed from nasal secretions for up to 3 weeks.

Bronchiolitis is highly contagious. The virus spread from person to person through direct contact with nasal or oral secretions, airborne droplets and fomites. RSV found in acute infection can survive on hard surface for approximately 6 hours and on soft surfaces for upto 30 minutes.<sup>5</sup>

## CLINICAL PRESENTATION

Infants become fussy and have difficulty with feeding.<sup>6</sup> They are present with low grade fever, hypothermia in younger infants, running nose, and irritating cough.<sup>7,8</sup> Concomitant otitis media is common.<sup>8</sup> Apnea may occur particularly in low-birth weight and preterm babies.<sup>8,9</sup>

Severe cases may progress over 2 to 5 days to the following signs and symptoms due to spread of virus to lower respiratory tract:<sup>10</sup> Cough, dyspnea, nasal flaring, tachypnea, tachycardia, irritability, fever, retractions, prolonged expiration, fine crackles (47%), diffuse fine wheezing, hypoxia and over-expanded chest.<sup>2,8,11</sup>

## RISK FACTORS FOR SEVERE DISEASE

Lower birth weight, younger gestational age,<sup>3</sup> age<12 weeks,<sup>12</sup> lower post-natal weight, caesarean section delivery,<sup>2</sup> underlying cardiopulmonary disease, immunodeficiency,<sup>3,12</sup> cystic fibrosis,<sup>13</sup> and multiple congenital anomalies.<sup>14</sup> The main risk factor for hospitalization is chronologic age, with 58-64% occurring in first 5 months after birth.<sup>15</sup> Other risk factors are positive RSV result, maternal age between 15-19 years, and maternal history of asthma and/or smoking.<sup>3,16</sup>

## IMPORTANT NURSING ISSUES

Good bed-side nursing care involves the recognition of deterioration that will necessitate treatment.<sup>8</sup>

### Repeated Clinical Assessment

Scheduled intermittent checks of pulse oximetry and heart rate should be done. The use of supplemental oxygen therapy is recommended when SpO<sub>2</sub> falls consistently below 90%. Factors to monitor include: cardiopulmonary monitoring, signs of increasing difficulty in feeding and associated risk of pulmonary aspiration, fatigue, work of breathing, and apneic episodes. Minimizing the impact of procedures (e.g. cannulation) as well as giving support and education to parents is also important.<sup>8</sup>

### Nursing Management at Home

Home O<sub>2</sub> is increasingly being used in patients with uncomplicated bronchiolitis and on-going hypoxia to reduce hospital admission and LOS.<sup>3</sup> Health setting at home is focused on improving respiratory functions, preventing dehydration and promptly identifying worsening respiratory functions.<sup>17</sup> Patient positioning should promote comfort and breathing. Activity that induce agitation should be avoided.<sup>3,17</sup>

### Patient Education

Education should be provided regarding the following:

- Natural history of bronchiolitis.

- Importance of RSV prophylaxis for high-risk patients.
- Importance of avoiding RSV exposure in the first 2-3 months of life and contact with ill people and day-care centers.<sup>2</sup>
- The importance of breast feeding, and avoidance of smoke.<sup>12,18</sup>
- The importance of vitamin D supplementation should be emphasized as a prospective birth cohort study demonstrated 6-folds risk of bronchiolitis if vitamin D is deficient.<sup>19</sup>
- Methods for limiting transmission (hand washing and avoiding childcare centers while ill).<sup>12</sup>
- Criteria for return to the ED.<sup>2</sup>

### Prevention of nosocomial transmission of infection

The following actions are needed as: Isolation or cohort nursing away from high risk infants,<sup>8</sup> strict hands washing before and after direct contact with objects in the patients' vicinity and after glove removal.<sup>20</sup>

Alcohol-based rubs or antimicrobial soap should also be used<sup>21</sup> plus the use of gloves, gowns, and face masks.<sup>3,18</sup>

Nursing role in updating the management according to the most recent guidelines and in advising other health professionals to omit some unnecessary diagnostic and therapeutic options. The justified use of only 2 or 3 truly needed diagnostic tests and also the concentration on the supportive treatment with oxygen, gentle suction and hydration instead of using unnecessary therapeutic options as bronchodilators, antiviral drugs, corticosteroids and/or antibiotics as discussed in the following section.

### DIAGNOSIS

The most common tests used in hospitalized cases with bronchiolitis, although most that are unnecessary, are:

1. Rapid viral antigen testing of nasopharyngeal secretions for RSV. Although this test has little significance on outcome it may influence treatment as physicians tend to stop antibiotics if it is positive. However AAP guidelines reported that it is unnecessary<sup>12</sup> as multiple viruses may cause bronchiolitis.<sup>3,12</sup>
2. Arterial blood gases: ABG analysis.<sup>9</sup>
3. WBCs and differential
4. C-reactive protein (CRP level)
5. ECG or Echocardiography is reserved to cases with arrhythmia or cardiomegaly.<sup>2</sup>
6. Chest radiography: It is not routinely necessary. Findings from chest radiography are variable. Hyperinflation is usually present and 20-30% show lobar infiltration, atelectasis or both. Other findings are bronchial wall thickening, flattened diaphragm, increased AP diameter, peri-bronchial cuffing, tiny nodules and linear opacities.<sup>22</sup>
7. Pulse oximetry is a good indicator of severity and if it is per-

sistently <92% indicates possible need for hospitalization.<sup>2</sup>

8. Electrolytes if the child needs IV fluids.<sup>3</sup>

9. Blood culture if temp > 38.5 °C.<sup>8</sup>

10. Other investigations are done only when needed as: Urine analysis and culture, CSF analysis and culture or urine specific gravity.<sup>2</sup>

Cultures and chest radiography and even CBC are unnecessary in previously healthy children as the risk of secondary bacterial infection is low.<sup>2,22</sup> These tests are considered only in severe disease, or very ill appearance, infants<3 months,<sup>9</sup> pre-existing cardiac or pulmonary disease, a markedly elevated temperature or other risk factor of more severe disease or when alternative diagnosis is suspected.<sup>3,8,9</sup>

In conclusion, many diagnostic tests for bronchiolitis are not needed in most cases. Diagnosis is based on clinical presentation, patient age, seasonal occurrence and findings from the physical examination. Few laboratory tests are necessary as oximetry and serum electrolytes. Other tests are sometimes needed to exclude other diagnoses as pneumonia, heart failure or sepsis.

The pediatric nurse has an important role here, to advise other health care professionals to exclude unnecessary diagnostic tests as radiology and viral detection to help to decrease the cost of management

## TREATMENT

DiNicola is an extensive review that states most therapies used to treat bronchiolitis are still controversial.<sup>2</sup> The authors addressed that issue extensively and reviewed previous literature and some of the guidelines till 2014.

Because no definitive treatment for the specific virus exists, therapy is directed toward symptomatic relief and maintenance of hydration and oxygenation.<sup>2,23</sup>

### Supportive Care

Supplemental humidified Oxygen *via* nasal prongs, facemask or head box is the only intervention known to improve outcome as it decreases V/Q mismatch caused by air trapping<sup>3,8</sup> and is recommended for previously healthy infants with oxygen saturations <90%<sup>21</sup> or 92%.<sup>2,8,9</sup> It was reported that, 90-92% in the recovery phase of un-distressed child is accepted.<sup>8</sup> Pulse oximetry monitoring is reduced as the clinical condition improves.<sup>25</sup>

As mild hypoxia is a major reason for hospitalization, treatment at home with Home oxygen therapy for those with hypoxia without other indications for admission was found to decrease need for hospitalization by almost 2 days with no difference in outcome.<sup>26</sup>

### Hydration

Mild cases should be fed more frequently in smaller amounts to be better tolerated and breast feeding shouldn't be suspended.<sup>13</sup> Moderate cases who cannot tolerate oral feeding and RR>50/min should receive NG feeding.<sup>2,18</sup> Intravenous fluids are needed in breathless infants and those with risk of pulmonary aspiration.

Overall fluid intake should be restricted to two thirds of standard maintenance fluid requirement, with blood electrolytes monitoring because of the possibility of inappropriate ADH secretion.<sup>3,9,20,25</sup>

### Nasal Suctioning and Saline Nasal Drops

Nasal congestion can be reduced by saline nasal drops (1-2 drops per nostril, 10-15 minutes before a feed 2-3 times/day for 3 days in hospitalized infant).<sup>2,26</sup> Nasal Suctioning may be used for inpatients. Superficial nasopharyngeal suctioning before inhalation and feeding and when needed may improve the work of breathing and feeding but excessive suctioning may increase nasal edema.<sup>3,18,26</sup>

Deep pharyngeal suctioning is not supported and is even associated with longer LOS.<sup>20,27-29</sup> The use of antihistamines, immunoglobulins, oral decongestants or nasal vasoconstrictors are not recommended.<sup>12,21</sup>

### Hypertonic Saline (HS)

It enhances mucociliary clearance by decreasing mucus viscosity. Evidence showed that it may decrease LOS by 25% and decrease admission.<sup>9,29</sup> In addition, Zhang, et al.<sup>30</sup> found that nebulized hypertonic saline in conjunction with bronchodilator may be effective in treatment and is better than 0.9% saline.

However, other studies show no short-term improvement in respiratory distress in ED.<sup>12,21</sup> HS is mostly safe without bronchodilators, inexpensive and apparently effective as an adjunct treatment in inpatient setting but not in ED.<sup>30,32-34</sup>

As regard mist-steam inhalation, there is insufficient evidence to show any benefit.<sup>13</sup>

### Bronchodilators: Short-Acting Beta2-Agonists

Beta-agonist effects reverse bronchoconstriction but evidence showed no difference in: hospital admission, LOS, oxygen saturation, or length of illness.<sup>9,18</sup> Some clinicians favour a trial of inhaled beta<sub>2</sub> agonists in a subset of patients (particularly>12 months age). Positive effects (25%) in clinical score after treatment may be observed but it is short-lived and should be weighed against potential adverse effects.<sup>9</sup>

Therefore it is not recommended for routine use and

experience suggests only a trial especially in older patients >24 months, family history of asthma,<sup>12</sup> or past history of wheezing and/or asthma.<sup>35,36</sup> Bronchodilators should not be continued unless an objective evidence of improvement is observed.<sup>2,21</sup> Recent evidence recommends against even a trial of bronchodilators (AAP Guidelines published online 2014)<sup>2,12</sup> as its possible effect of small short improvement has to be balanced against the risks of side-effects and costs, and the fact that it may contribute to agitation and V/Q ratio mismatching.<sup>20,36</sup> Ipratropium bromide has not been shown to be useful in bronchiolitis.<sup>8,37</sup>

#### Bronchodilators: Racemic Epinephrine

Beta-agonist properties reverse bronchoconstriction, while alpha-agonist properties cause vasoconstriction and reduce oedema. Evidence support that it is superior to placebo for short-term outcomes hospitalization within 24 hours but has no effects on: inpatient clinical course, vital signs, LOS and readmissions.<sup>2</sup> It is not currently recommended as it is not superior to saline, therefore, should not be given.<sup>2,9,12,20,38,39</sup>

#### Chest Physiotherapy (CPT)

CPT does not improve disease severity, respiratory parameters, LOS, or oxygen requirements.<sup>3</sup> Therefore, it is not recommended and is even discouraged as it may increase distress and irritability or cause rib fracture.<sup>12,20,25,39</sup>

#### Corticosteroids

Although it has anti-inflammatory effect, there is no evidence to support its routine use as studies showed no difference compared to placebo as regards: Admissions at day 1 and 7, LOS, and clinical score, therefore they are not effective and should not be used.<sup>20,21,41,42</sup>

#### Methyl-xanthine

As for RSV-bronchiolitis – associated apnoea, only cases series have shown a benefit of methyl-xanthine such as caffeine and theophylline as a consequence of their central respiratory stimulant effect while most severe cases may need ventilator support.<sup>13</sup>

#### Antibiotics

Concerns for bacterial infection: fever, young age, secondary infections, and severe cases. But evidence showed low rates of serious bacterial infection (1-12%). Urinary tract infection and acute otitis media are most common.<sup>9</sup> The use antibiotics should be restricted to those with specific indications for bacterial infection given that overuse increases overall antibiotic resistance.<sup>13,20</sup>

Azithromycin was tried because of its anti-inflammatory, immune-modulatory and antibacterial action but it didn't

alter clinical outcome, so it is not recommended.<sup>38</sup>

#### Humidified High-Flow Nasal Cannula (HFNC)

It may washout nasopharyngeal dead space and overcome nasopharyngeal resistance with flow, causing positive distending pressure and improved conductance and compliance. Retrospective reviews showed decreased need for intubation, decreased RR and decreased LOS in PICU with no adverse effects.

On the other hand, it was concluded that there is insufficient evidence to determine the effectiveness of HFNC (no clear evidence of decreased duration of O<sub>2</sub> therapy or LOS).<sup>43</sup> It may be useful in severe illness, but is not recommended for routine use.<sup>9,44,45</sup>

#### Continuous Positive Airway Pressure (CPAP)

There is no conclusive evidence to recommend CPAP but it may be useful in severely distressed patients to avoid intubation, increasing O<sub>2</sub> requirements, apnoea or rising pCO<sub>2</sub>.<sup>3,9,45</sup>

#### Intubation and mechanical ventilation

This is indicated for increasing hypoxia and respiratory failure despite the above measures. Exogenous surfactant administration and extracorporeal membrane oxygenation may also be considered in this subset of patients.<sup>3,9</sup>

#### Helium-Oxygen (Heliox)

Several studies have shown improved respiratory distress scores in patients breathing Heliox and have suggested that combined Heliox with nasal CPAP may render intubation unnecessary.<sup>47</sup> Helium has lower density than air so improve gas flow through high-resistance airways. It lower respiratory score and pCO<sub>2</sub> immediately but causes no reduction in rate of intubation, need for mechanical ventilation, or LOS in PICU. There is insufficient evidence for its recommendation as there is a need for larger trials with homogenous administration.<sup>3,48</sup>

#### Ribavirin

It is a broad-spectrum antiviral that inhibits RNA and DNA virus replication. Although it may reduce duration of mechanical ventilation and LOS; with possible decrease in subsequent wheezing episodes but the evidence showed that it has a controversial efficacy, it is expensive, cumbersome, has possible teratogenic and other health effects on caregivers. Therefore, it is not routinely recommended except in severe disease, or those at high risk for severe disease as immune-compromised, congenital heart disease, BPD, CF and other chronic lung diseases.<sup>12</sup> In addition, it may be recommended in hospitalized cases under 6 weeks or those having underlying multiple congenital anomalies or neurologic metabolic diseases.<sup>20,49</sup>

**Palivizumab**

A humanized monoclonal antibody directed against F (fusion) protein of RSV. Evidence showed a reduction in RSV-associated hospitalization in high-risk groups: chronic lung disease, congenital heart disease, and premature (<35 weeks gestation). However, there is no decrease in mortality or rate of recurrent wheeze; therefore, it is not cost-effective or beneficial for routine use in all infants. Owing to the expenses, its use is limited to patients at high risk of severe disease as healthy infants with gestational age <29 weeks or those with significant risk factors: Infants younger than 24 months who have hemodynamically significant congenital heart disease or who have chronic lung disease and are off oxygen or pulmonary medications for less than 6 months at the start of the RSV season.<sup>9,12,20,50</sup>

**Leukotriene Receptor Antagonists**

It is not currently recommended as it has no benefit compared with placebo in randomized trials as it did not shorten duration of illness.<sup>51,52</sup>

**FUTURE PREVENTIVE, DIAGNOSTIC AND THERAPEUTIC PERSPECTIVES**

Efforts to develop an RSV vaccine are ongoing.<sup>53</sup> Lambert, et al.<sup>54</sup> used BALB/c mice and cotton rats, two well-characterized rodent models of RSV infection, to evaluate the immunogenicity of intramuscularly administered RSV vaccine. These studies indicated that a protein subunit vaccine consisting of RSV sF + GLA-SE can induce robust neutralizing antibody and T cell responses to RSV, enhancing viral clearance.

Sun, et al.<sup>55</sup> found that maleic anhydride (ML)-modified human serum albumin (HSA), designated ML-HSA, administered intra-nasally before RSV infection had led to a significant reduction of viral titers in the lungs of mice. These results suggest that ML-HSA is a promising therapeutic candidate for further development into an effective, safe, and affordable intranasal regimen for pre-exposure prophylaxis of RSV infection in high-risk populations. Intranasal administration of small interfering RNA targeting specific RSV gene expression may change the approach to the treatment of bronchiolitis in the future.<sup>56</sup>

Future research is needed regarding controversial issues as diagnostic and therapeutic options for cases with bronchiolitis like the need for laboratory testing or radiology and also the value of using combinations of HS, bronchodilator and/or Heliox in therapy.

To summarize, the updated management of bronchiolitis, the most common cause of hospitalization of infants less than 1 year, has excluded many diagnostic and therapeutic options. Updating the management by discarding unnecessary options to make the management cost-effective and to improve outcome.

Only 2 or 3 diagnostic tests are needed instead of 10 tests. The only therapy that is truly needed is the supportive treatment with oxygen, gentle suction and hydration. Pediatricians and pediatric nurses should discard un-necessary therapeutic options as bronchodilators, antiviral drugs, corticosteroids and/or antibiotics which are still used in many hospitals..

The efficient updated nursing role in the care of infants with bronchiolitis should include the prevention care, observation at hospital and at home, and health education to parents. Furthermore, it should include the task of changing physicians' habitual use of un-necessary diagnostic and therapeutic options according to the more recent guidelines.

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