

Abstract from Current Literature

The voices of children and young people in health: where are we now?

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Universal children's day on 20 November 2014 marked the 25th anniversary of the UN Convention on the Rights of the Child (UNCRC, 1989) and the 55th anniversary of the Declaration of the Rights of the Child (1959). Twenty-five years after the UNCRC, this article explores the rights of children and young people (CYP) to participate in decisions about their healthcare, and the benefits of doing so; we then examine where we are now with respect to the voices of CYP in health. This article addresses this final question through three aspects: first, by celebrating the progress made over the last quarter of a century—particularly with respect to policy development—both in the UK and internationally; second, by identifying ongoing areas of concern, with suggestions as to where to focus our efforts next; and finally, by calling for a change in culture. This change of culture is suggested through four positive concrete steps: a greater dissemination of guidance and examples of good practice, greater evaluation of the participatory process, appropriate training and procedures in place to support CYP participation and finally encouraging increased involvement of CYP in improving their own health. Through these steps, we aim towards a culture where CYP are valued, heard, understood and, ultimately, their rights are respected.

Sudden unexpected death in infancy: aetiology, pathophysiology, epidemiology and prevention in 2015

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Despite the fall in numbers of unexpected infant deaths that followed the 'Back to Sleep' campaigns in the early 1990s in the UK and many other countries, such

deaths remain one of the largest single groups of deaths in the postneonatal period in many Western countries. Changes in the ways in which unexpected infant deaths are categorised by pathologists and coroners, and in creasing reluctance to use the term 'sudden infant death syndrome', make assessment of nationally and internationally collected data on incidence potentially inaccurate and confusing. In this paper, we review current understanding of the epidemiology and aetiology of unexpected deaths in infancy, and current hypotheses on the pathophysiology of the processes that may lead to death. We also review interventions that have been adopted, with variable degrees of effectiveness in efforts to reduce the numbers of deaths, and new approaches that offer the possibility of prevention in the future.

Don't stop now? How long should resuscitation continue at birth in the absence of a detectable heartbeat?

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Shah and colleagues from Western Australia present the latest in a series of papers, suggesting that outcomes for infants who have received prolonged resuscitation in the delivery room are more favourable than before. They report 13 near-term infants who had an Apgar score of 0 at 10 min and were admitted to intensive care. Five of the 13 infants survived and 4 of the 5 appeared to have normal development at 1–2 years of age (one of the infants had hearing impairment). One of the five survivors developed severe spastic quadriplegia.

Similar findings were reported recently in this journal by Kasdorf et al. They reported nine infants managed in a New York hospital, and combined their results with data from three of the therapeutic hypothermia trials and one other previously published report. In total, Kasdorf et al analysed a cohort of 90 infants with an Apgar score of 0 at 10 min who were admitted to intensive care. Fifty per cent of the infants survived to discharge from hospital, and 49% of the survivors were developmentally normal at follow-up at 1–2 years.

Longer-term developmental outcome data are available for a subgroup of these infants who were enrolled in the US NICHD cooling trial. Twenty four infants in that trial had an Apgar score of 0 at 10 min. Eleven (46%) survived to age 6-7 years, and 5/11 (46%) had mild or no disability at follow-up.

Considered together, these results are in striking contrast to earlier studies and should cause us to question current recommendations in consensus resuscitation guidelines.

Outcomes of infants with Apgar score of zero at 10 min: the West Australian experience

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Background: Infants who have an Apgar score of zero at 10 min of age are known to have poor long-term prognosis. Expert committee guidelines suggest that it is reasonable to cease resuscitation efforts if the asphyxiated infant does not demonstrate a heart beat by 10 min of life. These guidelines are based on data from the era when therapeutic hypothermia was not the standard of care for hypoxic ischaemic encephalopathy (HIE). Hence, we aimed to review our unit data from the era of therapeutic hypothermia to evaluate the outcomes of infants who had an Apgar score of zero at 10 min and had survived to reach the neonatal intensive care unit.

Methods: Retrospective chart review. Study period: 2007-2013.

Results: 13 infants (gestational age \geq 35 weeks) with Apgar scores of zero at 10 min were admitted to the neonatal intensive care unit. All were born outside the tertiary perinatal centre. Of them, eight died before discharge. The type and duration of follow-up varied. Of the five survivors, three had normal cognitive scores (100, 100 and 110) on Bayley III assessment at 2 years of age and one had normal Griffiths score (general quotient (GQ) 103) at 1 year. Only one infant developed severe spastic quadriplegia.

Conclusions: 4 out of 13 (30.7%) infants with 10 min Apgar scores of zero who survived to reach the neonatal intensive care unit had normal scores on formal developmental assessments. Information from large databases (preferably population based) is necessary to review recommendations regarding stopping delivery room resuscitation in term infants.

Prevalence and clinical significance of cardiac murmurs in schoolchildren

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Objective: To determine the prevalence and clinical significance of heart murmurs detected during heart disease screening among apparently healthy schoolchildren.

Design: Cross-sectional study.

Setting: 32 elementary schools in Dongguan City of China.

Patients: 81 213 schoolchildren aged 5-13 years from different elementary schools.

Main outcome measures: The prevalence and clinical significance of heart murmurs among schoolchildren.

Results: Murmurs were detected in 2193 school children (2.7%), of whom 215 had a structural heart disease (SHD). Of patients who had SHD, 198 children had congenital heart disease (CHD), 12 had mitral valve prolapse and 5 had rheumatic heart disease. In patients who had CHD, the most common diagnosis was a ventricular septal defect. With respect to sex, SHDs were equally distributed between males and females. Of the schoolchildren who had a murmur, 1797 (81.9%) had a murmur with the loudness of grade 1 or 2 and 396 (18.1%) had a murmur with the loudness of grades 3-6. The prevalence of SHD fell significantly with increasing age.

Thalassaemia in children: from quality of care to quality of life

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Over the past few decades, there has been a remarkable improvement in the survival of patients with thalassaemia in developed countries. Availability of safe blood transfusions, effective and accessible iron

chelating medications, the introduction of new and non-invasive methods of tissue iron assessment and other advances in multidisciplinary care of thalassaemia patients have all contributed to better outcomes. This, however, may not be true for patients who are born in countries where the resources are limited. Unfortunately, transfusion-transmitted infections are still major concerns in these countries where paradoxically thalassaemia is most common. Moreover, oral iron chelators and MRI for monitoring of iron status may not be widely accessible or affordable, which may result in poor compliance and suboptimal iron chelation. All of these limitations will

lead to reduced survival and increased thalassaemia-related complications and subsequently will affect the patient's quality of life. In countries with limited resources, together with improvement of clinical care, strategies to control the disease burden, such as public education, screening programmes and appropriate counselling, should be put in place. Much can be done to improve the situation by developing partnerships between developed countries and those with limited resources. Future research should also particularly focus on patient's quality of life as an important outcome of care.