#### TRACK 6: NURSING SCIENCE

Abstract no: 400

# Parent education on discharge instructions: A pilot study in Hyderabad, India

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Background/hypothesis: Everyday nurses worldwide assist patients and families in the transition from hospital to home. In economically developing countries, children with complex cardiac defects are currently receiving treatment for their chronic illness and are requiring more expanded parent education programmes to manage care after discharge. The aim of this study was to test the feasibility of training Indian nurses to conduct parent discharge teaching. The study team developed a sustainable computer-based nurse training, the PEDI programme, to increase nurses' knowledge and support role expansion. Our secondary goal was to validate culturally relevant training materials for parents and nurses.

Methods and materials: Institutional review board and ethics committee approvals were obtained. This investigation used a pre-/post- study design to evaluate user satisfaction, nurses' knowledge of discharge teaching content, and documentation of discharge teaching conducted with parents. After nurse training throughout a tertiary Indian paediatric heart hospital, individualised and group parent teaching post-operative training sessions were implemented on the ward. Convenience samples of 40 nurses, 25 parents, and 25 patient charts were obtained pre- and 6 months post-implementation of the PEDI programme. Focus testing of parents and nurses and retrospective patient chart audits were performed.

Results: There was a 15-point increase in nurses' discharge knowledge, from a mean of 80.6% - 95.7% (p=0.0005) after participation in the training. Nurses' and parents' reported high levels of satisfaction with the parent education materials (3.75-4 on 4 point scale). Evidence of discharge teaching in patient medical records improved from 60% (15/25 charts) to 96% (24/25 charts) after implementation of the PEDI programme.

Conclusions: Nurses can play an integral role in educating parents about post-operative care at home for children with complex cardiac defects. Future studies are needed to examine nurse-, child-, parent- and organisational outcomes related to this expanded nursing role in developing countries.

#### Abstract no: 420

## Effect analysis and nursing methods study of the modified Blalock-Taussig shunts operation in children with congenital heart disease

#### Lijuan Fu

Heart Center of Shanghai Children's Medical Center, China

Objective: By summarising the therapeutic efficacy of the Modified Blalock-Taussig shunts (MBTs) used in children with congenital heart disease (CHD), we aimed to study the methods of peri-operative nursing care and the reasons for complications, and to use the appropriate care countermeasures to increase children's survival rate and improve their living quality.

Methods: A retrospective study was performed to summarise the peri-operative treatment and nursing process and the following complications in 94 children undergoing MBT operations. The peri-operative monitoring and nursing methods includes: (1) All the children completed pre-operative examinations and low flow oxygen inhalation and prostaglandin EI were applied to prevent closure of the ductus arteriosus; (2) We monitored post-operative children's cardiac function and timely continuously; (3) We kept balancing intake and output, electrolytes and acid-base (4) Started to use peritoneal dialysis early on; (5) Implemented effective respiratory management; and (6) We strengthened the anticoagulant drug application and venous access management to prevent postoperative catheter embolisation.

Results: Ninety four children were studied. Seventy six children survived, 18 died and in-hospital mortality was 19.1%. The post-operative SPO2 of survivors increased, which was significantly improved when compared with pre-operation's SPO<sub>2</sub> (p=0.000). Fifteen children already had the radical operation performed and are doing well post-op.

Conclusion: MBTs is a good palliation for children with CHD, which could improve children's hypoxia conditions and increase pulmonary blood flow so as to improve the success rate of surgery. Rational use of oxygen, an early start with prostaglandin E1 use, strengthening post-operative cardiac function monitoring, implementing effective respiratory management, early using of peritoneal dialysis, accurate applying of anticoagulant drugs, comprehensive training on parents could significantly increase the surgical success and survival rate and improve the living quality of the patients.

# Abstract no: 863

# Paediatric cardiothoracic surgical site infection prevention: The multidisciplinary approach

## Ashley Nadine Hurford, Julie Plumridge and Di Robertshaw

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Background: Surgical Site Infection Prevention (SSIP) is a vital part of ensuring all patient's experience a complication free journey, though their health care experience. A great deal of research has been done in the adult health care setting on how to prevent surgical site infection. Still there remains little evidence of SSIP within paediatrics.

Method: Great Ormond Street Children's Hospital initiated an independent SSI team in 2010. The aim was to independently review in-patient's wounds on alternate days and follow them for 30 days post procedure. The cardiothoracic unit multidisciplinary team worked together with the department of infection prevention to establish a care bundle which would be suitable for cardiothoracic patients, from pre-admission to discharge. All patients now follow a specific care bundle which includes the following elements:

- Improved MRSA screening compliance;
- Patient Information on SSI and Surveillance;
- Pre-operative washing:

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- Patient skin preparation;
- Information post discharge;
- Unit protocol development on visitors, chest closure procedures on CICU, and wound care; and
- Timely investigations into all surgical site infections.

Essential to our work is the ability to follow our patient's journey through their recovery up to 30 days post-surgery; we believe we've extended our wound care programme into the community.

Results: The cardiothoracic unit has been able to follow-up 80% of all surgical patients. Our results show we have had a 10% reduction in SSI and we currently have a 1% infection rate for deep and organ space infections. We believe this is due to the multidisciplinary approach to the SSIP.

Conclusions: Since the monitoring process has been in place, we can demonstrate a reduction in infection rates, which ultimately improves our patient experience in their healthcare journey. We're now looking at extending and developing our methods further to continue our rate reduction.

## Abstract no: 930

# Researching outcomes of an educational intervention in the workplace: A flexible workforce fit for practice?

## Angie Johnson\* and Sheila McQueen#

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Background/Issue of concern: High dependency nursing of seriously ill cardiac children is fast-paced and requires a high level of attention to detail, outstanding assessment skills and deep critical thinking. These skills are not with the nurse on completion of basic registration training. During a time of change the matron identified a need for development in knowledge and skills of practitioners and made contact with the university.

**Aim/research objective:** The matron working in collaboration with UNN helped develop a simulation-based training module but ultimately wanted to know if following this intervention would be fit for practice? She also wished to know if the intervention made the nurses competent paediatric HDU practitioners.

**Process/method:** The education module utilises theory and practice through simulation and reflection on real practice which is grounded in real case studies to allow staff to develop the requisite knowledge and skills to recognise and provide emergency care for critically ill children. A collaborative journey began between the matron and the university's senior clinical academic which, in turn, resulted in nurse competence assurance in the recognition of the sick and critically ill child for nurses working in cardiac care.

Results: A research study carried out to assess the cardiac nurse's perception of the impact of the module concluded that this had enhanced the underpinning knowledge and improved clinical skills in the recognition and safe care of critically ill children.

Conclusions/implications: This has allowed continuing partnership working between academic and practice organisations to ensure that education modules and provision meets identified local and broader workforce development needs. Further research has taken place following on from this initial study.

#### Abstract no: 963

# Importance of a structured nursing assessment of a paediatric cardiothoracic patient: The positive response to change

#### Ashley Nadine Hurford, Claire Ranmal and Di Robertshaw

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**Background:** With the changing nursing role and the dependency of their cardiothoracic patients, the importance of patient assessment and excellent structured communication has been considered essential in maintaining patient safety.

Method: Great Ormond Street Children's Hospital cardiothoracic unit initiated a radical change from January to March 2011 in the way their high-dependency and low-dependency ward assessed their patients. The new structure was devised to recognise the in-depth assessment that is now required in simple and complex cardiothoracic patients. The implementation of the new structure was supported by senior nurses experienced in the advanced assessment of patients. As part of the development, the university affiliated with the Trust was also consulted, to ensure that the tool met academic standards. The nursing team concluded that to be succinct and effective, known structures of assessment would need to be adapted to create a new tool. The tools that were used in establishing the new structure were the ABC approach to patient assessment previously established by the Resuscitation Council UK and the "SBAR" approach originally devised by the naval military. The new tool was implemented over a 4-week period with small group training at patients' bedside.

**Results:** Following implementation our results showed 100% compliance with the tool. After 1 year we still maintain an average 95% compliance with the tool. Our figures are only affected by the employment of agency staff, which we are striving to train, to ensure we will again achieve 100% compliance.

Conclusions: We feel that we're achieving high compliance in the use of our tool as it has been designed by nurses for nurses and the simplicity of the tool is paramount to our successful implementation. We would now like to share our experience internationally.

#### Abstract no: 999

# The impact of modernising the way we nurse: A nurse's experience in moving their cardiothoracic ward to a newly designed and built environment

## Ashley Nadine Hurford, Di Robertshaw and Elizabeth Leonard

Great Ormond Street Children's Hospital, National Health Services Foundation Trust, London, United Kingdom

**Background:** The increase in patient numbers and the dependency of patients means the cardiothoracic unit needs to evolve. The availability of a new building to expand into is one that needs precise planning and communication.

Method: The cardiothoracic unit at our hospital expanded into a new building increasing capacity to 8 high- dependency beds, with 16 ward beds. The unit was designed to provide maximum privacy and well being for all patients. The nursing process required change as patients were to be nursed in single cubicles not open bays. The facilities of the unit were also improved for patients and visitors with break out rooms, play rooms and adolescent facilities. The change in nursing methods meant preparing the nursing staff was vital to the move. A system of training days were established to provide support in learning how to manoeuvre patients around the ward, carry out emergency procedures, become familiar with modern technology which would be available to the patients, as well as newly

designed patient safety equipment and technology. Nursing staff were given the opportunity to develop working strategies on team days, which were facilitated by senior staff. All strategies were implemented.

Results: The patients were all moved safely and effectively within 2 hours. All nursing staff completed a follow- up questionnaire to identify lessons to be learned for a further move in four 4 year's time. All staff stated they felt supported throughout their training and the effective communication they had regarding the move gave them confidence in caring for their patients.

Conclusions: We believe that by sharing our experience of transitioning to a new unit we can demonstrate that effective communication and empowering nurses to become involved in decision-making processes for establishing new workplace practice is the key to a happy, effective workforce and patient satisfaction is effective communication and empowering nurses to become involved in the decision making processes of establishing new working practice.

Abstract no: 1002

# Evaluation of a nutritional status intervention on children with congenital heart disease

#### Lijuan Fu and Tingting Zhang

Heart Center of Shanghai Children's Medical Center, China

Objective: Investigate the role of nursing in feeding intervention for children with catch-up growth. Methods: Children <6 months with non-cyanotic congenital heart disease (CHD) who underwent surgery from October 2010 - January 2011 at Shanghai Children's Medical Centre were selected by convenience sampling. Random allocation was taken to divide them into 2 groups (n=56 and n=58). The control group followed the current clinical feeding propaganda and education, while the experimental group were given feeding guidance from hospitalisation to post-discharge follow-up. During hospitalisation feeding guidance included knowledge of primary foods food knowledge especially for children with CHD, feeding behaviour, high-calorie food principles, etc. were given to the children's parents. In addition, a handbook "Feeding Guidance for Children with Congenital Heart Disease" was distributed for them at discharge. The nurses followed them up for 3 months and continued to guide the parents on how to feed according to their handbook. In this study, information was collected by Baseline Questionnaire for Children with CHD, Feeding Knowledge Questionnaire for Parents, Feeding Index Questionnaire, State Anxiety Inventory. The effect of the Feeding Guidance Follow-up Plan, which aimed at improving parents' feeding knowledge, regulating feeding behaviour and easing feeding anxiety was evaluated by Feeding Knowledge Scores, feeding index and the level of feeding anxiety.

Results: After following them up for 3 months, feeding knowledge of the caregivers improved (p<0.05), the feeding index was higher (p<0.05), and the levels of feeding anxiety significantly decreased (p<0.05) in the experimental group when compared with the control group. But there's no statistical difference on HAZ, WAZ, WHZ between the 2 groups (p >0.05).

Conclusion: By getting guidance on food and eating parents' knowledge could improve significantly; their anxiety regarding food proper preparation could be relieved, and feeding behaviour could be ameliorated short term; however, guidance failed to promote children's post-operative catch-up growth in the short run.

Abstract no: 1011

## Tetralogy of Fallot: Post-operative complications and nursing

# Yongmei Guan, Wenyi LuoLijuan Fu

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Objective: To provide evidence to the clinical nursing care through exploring and analysing the post-operative complications of Tetralogy of Fallot (ToF). Method: This retrospective analysis was performed to select patients < 1-year-old who underwent ToF operation in our hospital from January 2009 -December 2011, and to describe post-operative complications of these patients.

Results: 556 patients with different post-operative complications were selected for this study. The complications of low cardiac output syndrome, cardiac arrhythmia, ventilation-associated pneumonia, atelectasis, hypoxemia and pleural effusion ranked amongst the top 6 with 3.7%, 3.6%, 3.1%, 2.5%, 2.0% and 1.8% respectively.

Discussion: This study highlights the main complications in infant patients after ToF operation, provides evidence on nursing care, and guides nurses to take some preventive measures with regards to these patients.

Abstract no: 1031

## Stories from the heart: A protocol for interviewing children with complex congenital heart disease from Edmonton, Canada

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Background/context: Research on families and children living with complex congenital heart disease (CHD) has, to date, largely involved perspectives from care-givers and health care professionals, not the children themselves. Also missing is the perspective of their siblings. Children exposed to repeated invasive medical and surgical interventions from an early age face significant morbidity and considerable stress. The perspectives of these children are necessary to give direct voice to their experiences and effectively plan for intervention.

Purpose/aim: To identify evidence-based strategies for interviewing children for the development of an interview protocol to gain children's perspectives on living with complex CHD. The research question was: How can we best facilitate children and their siblings telling their stories about growing up with CHD? Methods and results: A protocol was developed based upon literature reviews regarding involving children in research. Key aspects of interviewing children incorporated into the protocol included: creating an atmosphere of trust and respect; obtaining consent; assent and maintaining confidentiality; engagement through the participatory process; the use of props and guiding questions to facilitate storytelling; and strategies to reduce power inequities. The protocol was piloted with children with complex CHD ranging aged from 5 - 15 years. The final protocol consists of a diverse repertoire of interview activities to elicit stories of children as well as contact with parents before and after the interview with the child.

Conclusion: Hearing from children as they live with complex CHD provides a voice for their experiences and needs. Their perspective also helps clinicians and researchers in planning for family-based interventions. This study provides valuable data regarding the feasibility of obtaining data through stories with this population and further contributes to the methodological literature concerning involving children with CHD in research.

# The relationship of child and family functioning in families of children with complex congenital heart disease: A pilot study

#### Gwen Rempel, Tamara Dorfman, Nicole Dahl, Laura Rogers and Joyce Magill-Evans

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**Background:** Parents play a critical role in optimal child development and healthy family functioning. Children who survive their complex congenital heart disease (CHD) live with chronic health issues and can have motor and cognitive disabilities that present parenting challenges. Understanding a range of parent perceptions and family functioning is foundational to developing interventions that optimise child, parent and family well-being.

**Purpose:** The purpose of this pilot study was to: (1) Describe a cohort of parents of children with CHD as per their parent and parenting characteristics (i.e. family management style, resilience and parenting stress) and their perceptions of their child with CHD (i.e. child's development, adaptive behaviours, and health-related quality of life (HRQOL)); (2) Identify trends through the analysis of individual family profiles; and (3) Determine if the questionnaires were effective in identifying the potential intervention needs of parents.

Methods and results: Questionnaires were sent to 24 families, with a total of 16 families responding. The mean age of the children with CHD was 7.1 years. Most family management styles were child/family focused. A significant difference on the resilience score was found between mothers and fathers. There was a large range in parenting stress, from within a normal range for total stress to a clinically significant range. The mean scores on all indexes of child development and adaptive behaviour were within the normal range. Regarding HRQOL, all children scored poorly on the dimensions of Heart Problems and Treatment, Treatment Anxiety, and Communication. Family profiles indicated higher parenting stress, lower resiliency scores, and a condition focused family management style in families with a child with more comorbidities, greater developmental needs, and suboptimal HRQOL.

Conclusion: Results indicate a range of parent and parenting characteristics. The questionnaires were effective in delineating the needs of parents at different stages of a child's CHD trajectory.

Abstract no: 1034

# What is the timing, setting, and nature of parent interventions for mothers and fathers of children with congenital heart disease: A scoping review

#### Gwen Rempel and Louisa Fricker

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**Background:** Evidence of the plight of parents of children with congenital heart disease (CHD) has been published soon after the 1st successful cardiac surgery programmes were established in the 1950s. Mothers have been the predominant source of parent data. Maternal anxiety, fear, stress, and uncertainty have been shown to influence child outcomes, although not in proportion to disease severity. Within this growing body of descriptive research there are repeated recommendations for parent interventions. The research question guiding this scoping review was: What are the timing, setting, and nature of parent interventions for mothers and fathers of children with CHD?

Methods: A scoping review was conducted with 707 articles identified from 6 bibliographic databases. Two reviewers independently screened articles by title and abstract for inclusion in the review.

Results: Thirteen articles representing 12 intervention studies from 10 centres published between 1975 and 2010 constituted the evidence base for this review. Most interventions occurred within the 1st few months of the child's birth and/or diagnosis. Most were conducted in the hospital or clinic. One study involved an interactive website and another evaluated a videoconferencing intervention. Seven interventions involved a combination of parent education and psychological support. Four studies concerned home-based management of anticoagulation therapy. Regarding study design, 7 studies had a comparison or control group, and 2 studies involved randomisation. Five studies included mothers only, 3 included mothers and fathers, and 4 studies did not specify numbers of mothers and fathers.

Conclusion: Interventions beyond the time of diagnosis are needed as parents face further transitions with their child such as additional surgeries and entering preschool. Timely parent intervention is required to optimise child and family outcomes. Settings other than hospitals and clinics are needed. Innovative technology to provide interventions at home and interventions for both mothers and fathers are needed.

Abstract no: 1073

# Evaluation of a short term educational strategy: Can this improve knowledge and confidence amongst participants in Iraq?

#### Stacey Marr, Frank Molloy and Caroline Lonsdale

International Children's Heart Foundation, Memphis, Tennessee, United States of America

Background: Congenital heart disease in the developing world creates a significant burden of disease and, to date the development of sustainable health systems that will treat and manage these conditions has not been a global priority. The International Childrens' Heart Foundation (ICHF) is a charitable organisation which collaborates with local teams in the developing world to build paediatric cardiac surgical programmes. This project aims to evaluate the effectiveness of a 2-week educational intervention in a paediatric cardiac intensive care unit in Iraq during a collaborative surgical visit. The research question is: Does a 2-week, mixed method educational programme have an effect on the knowledge and self-reported confidence level of participants in a paediatric cardiac intensive care unit in Iraq? There is little consensus about competence when applied to clinical practice, however, confidence and knowledge are attributes which have been closely linked with the ability to perform and have been shown to guide future behaviours (Macleod, et al. 2011).

Material and methods: Participants on the course will be asked to complete a pre- and post-course questionnaire: The ICU Education Evaluation Questionnaire (IEEQ) which has been designed and tested to measure knowledge and self-reported confidence levels before and after the educational intervention. The project will seek to establish correlation links between the identified variables namely: the education programme, knowledge and self-reported confidence levels of participants.

Results: Data collection 8 September 2012 - 22 September 2012: It is anticipated that there will be a difference in both confidence and knowledge amongst the group.

Conclusions: The ability of ICHF to tailor future educational interventions toward the requirements of the local team will improve the uptake of education and improve the competence of the whole team.

## Paediatric nurse practitioner managed cardiology clinics: Patient satisfaction and appointment access

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Background/hypothesis: Appointment wait times exceeded 40 days in the outpatient cardiology department at a children's hospital. To address the gap in available appointments, paediatric nurse practitioner managed cardiology clinics were implemented.

Materials and methods: A sample of 128 patients who presented concurrently in physician or paediatric nurse practitioner managed cardiology clinics was recruited for participation. The hospital's ambulatory patient satisfaction survey was utilised to measure level of patient satisfaction with care. Survey responses were evaluated using Fisher's exact test. Appointment wait times were compared pre- and post-implementation of paediatric nurse practitioner managed clinics. Results: Sixty five physician and 63 paediatric nurse practitioner families completed the satisfaction survey. There was no statistically significant difference in patient satisfaction between clinic types. Appointment wait time decreased from 46 - 43 days, which was not statistically significant, but clinically important. Paediatric nurse practitioner clinics evaluated a statistically higher percentage of urgent appointments compared to physician clinics. With the addition of several weekly nurse practitioner managed cardiology clinics, current wait times in the outpatient cardiology department are now less than I week.

Conclusions: Paediatric nurse practitioner managed cardiology clinics are a strategic solution for improving patient access and facilitating high quality patient care while earning high levels of patient satisfaction. This healthcare delivery model illustrates successful expanded utilisation of advanced practice nurses.

Abstract no: 1180

# Percutaneous pulmonary valve implantation: Experiences of the patient and his/her close relatives

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Background: Percutaneous pulmonary valve implantation (PPVI) reduces the number of open-chest procedures during childhood and adolescence. As operative survival has improved, the focus of PPVI has turned to quality-o- life aspects and the way in which patient assessed experienced treatment. This study evaluates the physical and psychosocial aspects of daily life in patients, and relatives, undergoing PPVI.

Methods: Ten consecutive patients were included in the prospective, qualitative study from April 2007 - June 2011. Patients and close relatives participated in individual in-depth interviews I day before and 3 months after PPVI. All patients and close relatives had previous experienced cardiac surgery and subsequent paediatric cardiac intensive care.

Results: This less invasive procedure resulted in an earlier return to daily life and activities compared with previous experience (median 2.4 days in hospital) with patients resuming their social role and function. Close relatives stated that both the short hospital stay and improved function of their child was of benefit for the child, the family and society.

Conclusion: This study shows that striving for normality of life is a main goal for both patients and their relatives. In facilitating patients to achieve optimal social function in school, the home and with peers, PPVI appears to offer a favourable approach, due to the minimal interference on daily life. Furthermore, this study allows for the evaluation of our health system from both a patient and a family perspective.

Abstract no: 1268

### Increased knowledge required in adults with rheumatic heart disease: The Cape Town experience

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Background: The REMEDY study is a comprehensive, contemporary data collection on patients with rheumatic heart disease (RHD). It is a hospital-based international registry in progress involving 20 sites in Africa and India. This abstract focuses on the patients enrolled at Groote Schuur Hospital (GSH) in Cape Town.

Method: Over a 2-year period 420 patients with RHD were interviewed and enrolled onto the REMEDY study from the cardiac clinic out-patients department at GSH. At enrolment demographic data, clinical findings, treatment practises, ECG and echocardiographic details are recorded onto structured record forms. Results: Amongst a study population of 420 patients 52% of the patients are in the age group 30 - 50 years. 8% are severely debilitated in their daily functioning (NYHA III + IV). According to the patients' past medical history, 6% have had major bleeding, 19% stroke, 19% valvuloplasty and 66% valve surgery. A total of 44.7% had been prescribed oral anti-coagulation therapy. Of concern was the finding that 40% of patients had 2 or less INR measures in the previous 6 months, while only 4% had monthly INR checks. In addition, 62% did not know what their goal INR should be. Only 14% of patients had been prescribed secondary prophylaxis, although 66% have had surgery.

Conclusion: These preliminary results highlight the need to improve the knowledge of both health practitioners and patients with regards to treatment practices.

# A pilot study of a skin-to-skin care intervention in infants with congenital heart defects

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**Background:** Infants born with complex congenital heart defects (CCHD) demonstrate impaired parasympathetic nervous system function. Early separation impairs infant parasympathetic function, and newborn infants with CCHD and their mothers are often physically separated due to the infants' need for intensive care. Skin-to-skin contact (SSC) is effective in improving infant parasympathetic function in other high-risk infant populations. This study examined the feasibility, acceptability, and safety of an intervention designed to enhance infant parasympathetic function through daily SSC between mothers and newborn infants with CCHD.

Methods: Ten infants with CCHD and their mothers were recruited. Mothers provided at least 1 hour of SSC for 14 consecutive days post-operatively shortly after initiation of nipple feedings. Feasibility and acceptability were measured with a survey and mothers' written records of duration and frequency of holding. Safety was measured by infants' cardio-respiratory stability during SSC. Measures of parasympathetic function, as indexed by high frequency heart rate variability (HF-HRV), were collected at feedings before and after the intervention and bi-weekly for 4 weeks.

Results: Mothers provided a daily mean of 66.58 (SD=4.85) minutes in SSC over the 14-day intervention. Mothers were positive in their evaluation of SSC, and no adverse events occurred. Improvements in parasympathetic function over time were demonstrated with: (1) Developmentally appropriate increases in the magnitude of baseline (pre-feeding) HF-HRV (t =40.01, p <.001; (2) consistent improvements in time to post-feeding HF-HRV recovery as calculated using event history analysis; and (3) gradual permanent improvements in adaptive parasympathetic responses to feeding in 6 of 10 infants as calculated using ARIMA time series analysis.

Conclusions: SSC is a safe, feasible and acceptable intervention for infants treated for CCHD as neonates. Improved parasympathetic responses to feeding were demonstrated. A randomised clinical trial is needed to more closely examine effects of SSC on parasympathetic function.

#### Abstract no: 1439

# Frequent adverse events in infants with single ventricle anatomy during the interstage period

#### Patricia O'Brien, Margaret Schroeder, Sarah Sinclair, Sonia Handa, Jean Connor and Michelle Steltzer

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**Background:** Infants with single ventricle anatomy s/p Stage I repair or those with shunt dependent lesions are at continued risk for morbidity and mortality during the interstage period. Home monitoring programmes (HMP) were developed to detect worsening oxygen saturations, dehydration and growth failure. This study reviews interstage adverse events in infants followed in a HMP.

Methods: Single centre retrospective review of 53 infants with single ventricle anatomy who were in a HMP during the interstage period (time from initial discharge to Glenn procedure) over a 2-year period, 2009 - 2011. Interstage adverse events (changes in oxygen saturation, poor feeding or poor weight gain, inter-current illness and other health problems) were evaluated.

**Results:** There were 32 infants with HLHS (60%), and 21 infants with other types of single ventricle, interstage mortality was 5.5%. Average interstage period was 119 days. There were 145 adverse events; 50 for changes in saturation, 46 for poor feeding or inadequate weight gain, 29 for inter-current illnesses (bacterial and viral infections) and 19 for numerous other health problems. While not specifically targeted in HMP, infections and other medical problems comprised 33% of events. Management involved ER evaluation for 17 events, and 73 hospital admissions. There were 33 unexpected catheterisations or surgical procedures. Eight patients (15%) had no adverse events, only 2 patients with HLHS had no events. Eleven patients (21%) had more than 5 events. Of the 9 patients with NG- or G-tube feedings, all had 1 or more adverse events. Nine patients (17%) needed prolonged hospital care.

Conclusion: HMP detected many adverse interstage events of varying etiologies which were frequent and often required hospitalisation. A third of the adverse events involved inter-current illnesses or other medical problems. Patients with NG- or G-tube feeds and those with HLHS were more likely to have adverse events.

## Abstract no: 1466

## Characteristics of post-operative cardiac surgical patients readmitted to paediatric ICU

## Rebecca Tracey

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**Background:** The Paediatric Intensive Care Unit (PICU) is a 20-bed integrated general and surgical unit within a university-affiliated tertiary children's hospital. The hospital performs approximately 700 cardiac surgical procedures per year, providing comprehensive care for the treatment of neonates, infants, children and young adults with complex congenital cardiac lesions. The PICU Liaison Programme was developed in 2005 to facilitate discharge and support patients and families on the wards. In an effort to reduce readmission rates to PICU the Liaison Nurse team developed a risk management tool known as the Clinical Marker Score (CMS). It is used to identify predictive risk factors for readmission during the discharge and follow-up process. The tool is a combination of both objective and subjective score components derived from a case--control regression analysis of PICU discharge and readmission data. It is a generic tool used on both PICU patient populations prior to discharge and on every follow-up visit by the Liaison nurse.

Aim: To test the hypothesis that predictors of readmission will vary across the general and cardiac surgical patient population in the PICU. The purpose of this study is to describe the characteristics of cardiac surgical patients readmitted to the PICU.

Methods: This is a retrospective review of all post-operative cardiac surgical patients readmitted to the PICU within 72 hours of discharge. The data period was from January 2005 - June 2012. No interventions were performed in this study.

Results: There were 4 368 cardiac surgical patients discharged from PICU during this 6½-year period. Of these, 197 (4.5%) were readmitted. The most common cause for readmission was respiratory dysfunction, primarily resulting from effusions, infection or upper airway obstruction. The 2nd highest cause was cardiovascular dysfunction, predominantly sepsis, cardiac failure or arrhythmias.

Conclusions: Respiratory complications were the most common cause for early PICU readmission among paediatric cardiac patients. Further development of the subjective/objective score components specific to this patient group will improve discharge planning and avoid readmission to the PICU.

# Academy of cardiovascular excellence: Development of a cardiac curriculum for professional development of staff in a paediatric acute care hospital setting

#### Kas Sheehan and Susan Collins

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Background: Caring for patients with congenital heart disease pose many challenges which may impact clinical performance, productivity, patient safety and outcomes. These challenges are constantly changing due to many factors, such as staff turnover and skill mix, continued technological advances in care and increasing complexity of children and adults presenting with paediatric cardiovascular disease. We determined a need for a standardised cardiac educational programme that could be offered to all staff on an ongoing basis, providing an opportunity for continued development of knowledge and critical thinking skills, necessary to meet these challenges. The Academy of Cardiovascular Excellence (ACE) was developed.

Materials and methods: In 2008, a multidisciplinary group with representatives from the Cardiovascular ICU, cardiac catheterisation lab, cardiac operating room and non-invasive cardiology in a paediatric acute care hospital met frequently to discuss the development of this programme. Discussion centered around the core knowledge based objectives that were felt to be essential in providing care to this patient population along the continuum of care, encompassing all of these clinical areas.

Results: A 48 hour core curriculum was developed and offered over an 8 week period, 6 hours each week, offered 3 times per year at a minimum. Didactic sessions, group discussion, and case based scenarios promoting critical thinking allow for application of content to the participant's specific practice area. An 18 hour advanced curriculum, offered in 3 sessions, 6 hours each, enhances the core knowledge provided in the core curriculum.

Conclusions: Course evaluations have indicated a high level of satisfaction with the content and delivery of the ACE programme as well as providing feedback related to opportunities for improvement in the course content since it's inception. The programme continues and is evolving further to meet the changing needs of the patient care environment.

Abstract no: 1714

# Neonatal screening with pulse oximetry in 10 858 neonates: Multi-centric project in Northeast Brazil

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Introduction: Congenital heart disease accounts for approximately 9 in every 1 000 neonates. Early diagnosis and treatment is needed in about a third of the cases. When optimised, the arterial pulse oximetry test (POT) adds to physical examination as a low cost and efficient screening tool.

Objective: To report the results from arterial pulse oximetry and physical examination with a telemedicine network established between 2 States in Northeast Brazil.

Methods: Multi-centric, descriptive, prospective study from 12 centres between January - July 2012. Nursing teams from all centres were trained to collect data and input it in a database. POT was considered normal when 2 exams, from right arm and one foot, had SpO2 >95% and the difference between them was below 2%. Physical examination focused on the presence of murmurs and examination of peripheral pulses. Neonates with abnormal physical examination or POT were referred to a neonatal screening echocardiogram.

Results: A total of 10 858 POT were performed; 554 were abnormal and 214 babies were referred to a screening echo performed by a neonatologist under cardiology supervision. 138 abnormalities were detected. The relation between abnormal POT/collected POT decreased from 14.8% in January to 3% in July. The number of echoes performed was below the number of abnormal POTs except in July.

Conclusion: Neonatal screening for CHD in the State of Paraiba started this year and has already evaluated over 10 000 neonates. The fall in abnormal POTs in recent months reflects a learning curve with the test. When isolated, POT accounted for the detection of 15.5% of CHD, the remaining cases being screened by physical examination alone (81.2%) or physical examination and POT (3.3%). The POT test is easy to perform but requires training and the establishment of routines to be reliable. Physical examination remains the most important tool for screening for CHD.

Abstract no: 1780

## Factors influencing meaning of life in adolescents with congenital heart disease

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Purpose: This study was designed to identify variables associated with meaning of life in adolescents who underwent cardiac surgery for congenital heart disease (CHD).

Methods: Data were collected from 120 adolescents, aged 15 - 18 years with CHD, during outpatients' clinic follow-up after open heart surgery in one major cardiac centre in Korea. Adolescents completed measures of meaning of life, self-esteem, self-control, parental attitude, parental attitude, family satisfaction, school adjustment and career maturity. Their New York Heart Association functional class and non-invasive saturation of arterial oxygen were also measured. Result: The mean total score for the meaning of life scales was 2.05 points, which was slightly low. There was a significant relationship between meaning of life

and self-esteem, self-control, parental attitude, family satisfaction, school adjustment, family satisfaction, school adjustment, career maturity and functional class. The multiple regression analysis also showed that 53% of the variance in meaning of life in adolescents CHD could be explained by self-esteem, family satisfaction, school adjustment, parental attitude and functional class.

Conclusion: These results indicate a need to develop nursing interventions to increase self-esteem, family satisfaction, school adjustment, parental attitude and functional class in order to improve meaning of life for adolescents with CHD.

## Severe left ventricular non-compaction in early childhood

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**Background:** Left ventricular non-compaction is characterised by hyper-trabeculated myocardium. There are deep recesses communicating with the left ventricular chamber where blood penetrates with risk of clots developing. Adult prevalence is estimated at 50 per 100 000 but only 2% will develop symptoms within the 1st decade of life. We present a case of an infant.

History: A 4-week-old male infant developed poor feeding and increasing breathlessness. He presented collapsed and shocked at 6-weeks of age requiring intubation and inotropic support. His worst gas had a pH of 6.96 with a lactate of 16. Echocardiogram revealed a poorly functioning hypertrophic dilated left ventricle with non-compaction. After 1 week he was extubated. Receiving regular anticoagulation, diuretics and beta blocker treatment he remained clinically asymptomatic for the next 12 months other than for frequent respiratory infections. He grew and developed normally despite dramatically poor echocardiographic left ventricular function (rocking left ventricle with fractional shortening <10% and abnormal speckle tracking). He was negative for Barth syndrome testing (a known association). At age 1 he rapidly decompensated requiring ventilation and inotropes. There was no improvement and he was urgently listed for cardiac transplantation. Unfortunately he died from an intracranial haemorrhage whilst on a Berlin Heart Ventricular Assist device awaiting transplantation. This case was particularly challenging as the prognosis was so uncertain with poor outcome reported in 25% of children whilst others remain asymptomatic, causing the family great difficulty with regards to coping. From the onset we were open in sharing the child's uncertain future with the family, giving psychological as well as medical and nursing support. This child was relatively well until final deterioration.

Conclusion: Left ventricular non-compaction in childhood is relatively rare and has a variable severity and an undulating course. This case demonstrates a severe end of the spectrum.

#### Abstract no: 1813

# Parenting/care-giving work of mother and father couples who have an Infant with a complex congenital heart defect

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Background/objectives: Parents of infants with a complex congenital heart defect (CCHD) often describe care-giving demands and challenges. Little is known about how parents manage care-giving as a couple through the infant's 1st year. Although parents have identified the other parent as the most likely source of support, they have also described providing this support as the most challenging aspect of parenting.

Objective: To learn what parents were working together on to parent and give care to an infant with a CCHD through the 1st year, how they approached care-giving, and reach agreement or sort out differences in perspective about the infant or about parenting/care-giving.

Materials and methods: Parents (mothers and/or fathers) of an infant with a CCHD were interviewed in their homes at 1, 4 or 6, and 12 months after the infant's birth. Parents responded to semi-structured interview questions concerning parenting experience, including what parents were working on, a question to learn about motivations, goals, and intentions concerning the infant, self, and the parent couple.

**Results:** Among 21 care-giving parents, including 3 fathers, approximately half were doing parenting work as a couple, 30% were attempting to parent as a couple, while the remainder had no prospect of couple-parenting. Disagreement on infant condition or what the baby needed for care or parenting was higher when couples were not parenting together, either cooperatively, collaboratively, or in tandem.

Conclusions: Difference in perspective on infant need may put couples at risk for difficulties with parenting/care-giving. Motivations for parenting/care-giving changed for some couples through the infant's 1st year. Two motivations likely to have continuity were to maintain the couple's relationship with the qualities it had before the infant's birth, and to keep attuned to each other, e.g. to "stay on the same page". Studies of support structures for couples' accomplishment of parenting/care-giving goals are needed.