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Original Article

Learning and evolving*

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It is an honour to present the Anthony Chang lecture at this 10th International Conference of the Pediatric Cardiac Intensive Care Society. I have had the privilege of knowing Dr Chang for over 20 years, and although we only worked for a short period of time together at the Children's Hospital, Boston, in the Cardiac Intensive Care Unit, we have remained close colleagues and friends since that time. The contributions of Dr Chang to the development of paediatric cardiac intensive care are very clear, based on his clinical expertise, research and scholarship, and the development of the Pediatric Cardiac Intensive Care Society in its early days. More than this, Dr Chang is an individual with vision; in many respects, he has been ahead of the curve, anticipating and leading the direction of paediatric cardiac intensive care.

My presentation today is based on learning and evolving, with themes related to the journey of paediatric cardiac intensive care, some challenges ahead, and what I believe to be unique opportunities moving forward.

As with any journey, there are personal components, and I am mindful of my upbringing in Melbourne, Australia, the support and foundation provided by my wife and children, and an inspiration for the future through my granddaughter Emery May. Where we come from, our support, retreats, and pleasures all define us and are integrally related to our professional careers. My professional career and interest in paediatric cardiac physiology started as a final year medical student when I undertook an elective in Kundiawa in the central highlands of New Guinea. A spectacular yet isolated part of the world, I was very fortunate to meet one of my early mentors, Dr Frank Shann. A 2-year-old presented at Kundiawa Hospital with severe heart failure and low output state. Dr Shann, who was working at the Goroka Hospital, also in the central highlands, had travelled to Kundiwa that particular day to review patients and meet with staff as he commonly did. Dr Shann thoroughly reviewed this struggling 2-year-old, diagnosed the patient with a likely past history of rheumatic fever leading to severe mitral stenosis with left atrial and pulmonary hypertension. Time was spent discussing the unique pathophysiology associated with this disease and from that point on I was "hooked". Physiology in effect came alive and this has continued throughout my professional career in paediatric anaesthesia and intensive care. I was again fortunate to be a Fellow and work on staff at the Royal Children's Hospital in Melbourne under Dr Shann, and it was during my time there that I started to form my first long-standing professional connections – namely, the Fellows in my class. We have all had this experience, and maintaining those relationships across the years and across oceans has been very rewarding.

In 1992, I moved to Children's Hospital Boston and was very fortunate to work with another of my mentors, Dr David Wessel. In particular, the experience of working at the Royal Children's Hospital in Melbourne and Children's Hospital Boston afforded me the opportunity to work in centres of excellence, where the goals are innovation and adaption, with high complexity and relatively lower volume specialties. In such environments, centres of

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excellence strive to shift the mean rather than specifically shift clinical behaviour. This period was the late 1980s and 1990s, which really was the birth of paediatric cardiac intensive care. It came on the heels of tremendous innovations in cardiology, cardiac surgery, and cardiopulmonary bypass. It was a time when we started to understand the importance of cardio-respiratory interactions, adapted new strategies for the management of pulmonary hypertension, and learned about the challenges associated with neonatal and infant cardiac surgery, particularly the systemic inflammatory response. We learned to control the stress response as a means to limit some of the consequences of the systemic inflammatory response, and started to appreciate the risk for neurological injury after neonatal and infant cardiac surgery. During these years, there was great innovation and discovery across the disciplines managing children with heart disease. In many respects, the innovation and discovery required adaptation of strategies used for managing adults, and was way ahead of technology available for infants and children at that time. New monitoring and mechanical support devices were in their infancy in many respects, and certainly the ability to capture and use data and leverage computing technology was not possible. Perhaps the best examples of the development of paediatric cardiac intensive care are the early studies evaluating the postoperative course in infants who had undergone cardiac surgery, in particular the work from Children's Hospital Boston evaluating the time course and evolution of haemodynamic changes after cardiac surgery. The work by Wernovsky and Wessel et al in the Children's Hospital Boston Circulatory Arrest study was the first to demonstrate the fall in cardiac index that occurs some 6 to 12 hours after cardiac surgery and the relationship with an increase in pulmonary and systemic vascular resistance.[1] Such work in particular helped us define our specialty and transition from being cardiac-centric to that of a critical care focus on how to optimise the balance between oxygen supply and demand.

Another very important lesson and experience during these early years at the Boston Children's Hospital was my appreciation for the value and importance of leadership in nursing within paediatric critical care. Dr Patricia Hickey was the nurse manager of the Critical Care Unit at the time, and through Dr Hickey and so many other nurses in the Cardiac Intensive Care Unit at Children's Hospital Boston, I learned to appreciate the importance of collaborative practices, sharing opinions and ideas, particularly related to quality and patient safety, and the evolution of the nursing profession to that of a science.

Without labouring these points further, it is important to emphasise that this early era of paediatric cardiac intensive care was exciting with rapid cycles of learning and evolution. To be able to be part of these early days was immensely gratifying. As I will discuss later, I believe we are at a similar point in time right now, both in our profession and the opportunities that are before us.

In 2012, I moved to the Hospital for Sick Children in Toronto as Chief of the Department of Critical Care Medicine, and once again have had the privilege of working with clinicians who have shaped our field, as well as those who are leading new innovation. Some of the challenges we face currently in healthcare related to cost containment are not new. I recently reviewed a number of leather-bound journals maintained by Dr Al Conn, the first Chief of the Department of Critical Care Medicine at SickKids. These journals were meticulously maintained from 1970 through 1990 and are a wonderful archive of the development of paediatric critical care at SickKids. It is interesting to note that the challenges related to workflow and outcome measures were no different 30–40 years ago, and indeed the discussions around the escalating costs of critical care were very much evident at that time.

As a specialty, we have evolved substantially. We are recognised as an integral component of cardiac programmes for children with heart disease and have developed our science across disciplines. There are challenges ahead, and I wish to outline four of them that I believe are important for us to consider.

Modifiable risk in critical care

We need to understand the contributions critical care management has on patient outcomes; indeed understanding these contributions should be a target for measuring performance and improvement. It is well-appreciated that the length of stay after infant heart surgery is associated with worse longer-term neurodevelopmental and cognitive outcomes; however, the particular factors contributing to this are still being defined.[2,3] Length of stay is perhaps a surrogate for the complexity of the underlying disease and the intensity of therapy, but may also reflect our management styles and practices. More recently, this was evident in the Single Ventricle Reconstruction trial.[4] The primary outcomes from this study are well-known, but I want to note an important paper from this study that evaluated the risk factors for early hospital morbidity and mortality after the Norwood procedure.[5] In the early recovery phase, there was no difference in the mortality between either the right ventricle to pulmonary conduit, commonly referred to as the Sano operation, or the traditional Norwood procedure in which a modified Blalock–Taussig shunt was the source of pulmonary blood flow.

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Indeed, there was no difference between either shunt type with respect to time to initial extubation, duration of ventilation, total ICU stay, hospital stay, and the per cent of patients managed with open sternums. Indeed, no modifiable factor related to the care provided in our ICUs following Stage I palliation could be identified. In both patient populations, there was a significant decrease in survival associated with extracorporeal membrane oxygenation or cardiopulmonary resuscitation, and this provides a window for us for potential improvement. Although the data were not available in the Single Ventricle Trial, it is likely that there were a number of circumstances in which the risk for cardiac arrest or extracorporeal membrane oxygenation could have been identified before these events occurred, and early anticipation and introduction of alternative therapies may have resulted in improved outcomes. This is speculative of course, but it highlights the fact that we need to evaluate our performance in a much better way.

We all measure certain events within our critical care units to measure quality and safety, as well as our overall performance. Metrics include healthcare-acquired infections, unplanned extubation, re-admission rates within 48 hours, medication safety, specimen integrity, pressure care, and adherence to various policies and procedures. To understand performance, however, we need to examine more closely our ability to be predictive and prevent events. Cardiac arrest is one such event that can be measured, although the frequency is relatively low within our ICUs and it is hard to apply robust analytics to low-frequency events. Nevertheless, up to a quarter of cardiac arrests may be deemed possibly preventable (Laussen, unpublished data from Boston and Toronto), and understanding the circumstances around these events is an important area for study and measurement of performance. Indeed, we can rescue patients very effectively in our ICUs; however, the *failure to rescue rate* is not the metric we should be aspiring for. Rather, it is a *failure to predict* that should define our performance and value.

Understanding workflow and practice variability

Just as failure to predict should be an important performance metric, so should our ability to provide a safe and efficient patient journey. We know there is great variability among our institutions in the way we approach the management of certain disease and in management practices within ICUs,[6] but in many circumstances there is no reason why these should not be standardised. To do so, we need to map a safe and efficient patient journey. It starts from admission with a known disease or procedure to which we apply various risk adjustments, such as Risk Adjustment for Congenital Heart Surgery, and acuity metrics, such as Pediatric Risk of Mortality Scoring System or Pediatric Index of Mortality Scoring System, to determine what our expected outcome should be at the time of discharge. We overlay various guidelines and protocols, early warning systems, and quality metrics throughout the patient journey, along with benchmarks related to mortality and morbidity to ensure we are comparable with other similar institutions. Of course we rely on a myriad of monitors and devices that deliver treatment and collect information that is fed into an electronic health record, from which we are meant to be able to assimilate information to inform our decisions. Throughout this patient journey, and despite this overlaying network of guidelines, protocols, monitoring, and devices, we still bounce around in our decision-making and follow quite different treatment nodes. The reason for this on part relates to our hierarchical culture, and competitive nature between institutions with respect to outcomes, but more so perhaps within an ICU, it relates to the way in which we work and in particular the multiple parallel tasks and time pressures that we all face within a resource-intensive and complicated environment. These environments are increasing in size and footprint, which results in fragmented and diffuse communication and visibility, and too often we rely on individual judgment and intuition rather than on analytic decision making. Indeed, being able to capture our decisions with the data and information is a very important step for us in the future.

One of the most rewarding aspects of my professional career has been helping organise Risky Business conferences. These were first started by Dr Alan Goldman, Dr Tony Giddings, and Guy Hirst in 2006 and I joined them in 2007. Over the last 8 years, we have held numerous free-standing and satellite conferences on risk management within healthcare, trying to understand and learn from other high-risk industries. Among the speakers at the first conference in 2006 was Sir Sydney Watkins, the Chief Medical Officer for Formula One at the time. Following the tragic death of Ayrton Senna in 1994, Dr Watkins led a major overhaul of all aspects of safety in Formula One racing. Between 1953 and 1994, 37 drivers lost their lives during Formula One races. Since 1995, with the changes to car and cockpit design as well as safety regulations across the industry, there have been no deaths in Formula One racing! This is an industry from which we can learn a great deal. For example, the pit crew analysis is often used within safety and quality science to highlight the importance of teamwork, process organisation, and both threat and error management. First studied in the Cardiac Intensive Care Unit at the Great Ormond Street,[7] the philosophy of teams working similar to

those of pit crews has spread across healthcare and the simulation field. Nevertheless, there are other lessons to be learned from this industry, in particular the way in which they obtain and use data, but more of this is to follow. The point is that there are many industries that have dealt with similar problems that we face in paediatric cardiac intensive care and valuable lessons can be learned.

The transition from paediatric to adult care of patients with CHD

Although the birth rate and frequency of CHD in infants and children remain relatively static, adults with CHD is a rapidly increasing patient population. This has been emphasised in the guidelines for the management of adults with CHD published by the American Heart Association[8] and other societies such as the Canadian Cardiovascular Society 2009 Consensus Conference.[9] In these statements, systems for care and follow-up, and aspects of cardiac surgery and cardiology necessary to improve the care for this increasing and challenging patient population, are well-described; however, there is very little information regarding the critical-care management of adults with CHD, and yet they carry a substantial pathophysiologic burden with them. This is perhaps highlighted by the most recent study by Yves d'Udekem in a paper evaluating the 25-year follow-up of a large population of long-term survivors following the Fontan procedure in Australia and New Zealand.[10] This registry is a rich source of information, and describes the freedom from adverse events at 20 years following the Fontan operation as being <50% and freedom from failure of the Fontan procedure as <75% at 20–25 years. The Fontan circulation is unique to paediatric cardiac intensive care. We understand the physiology and have evolved important strategies for optimising flow across the pulmonary vascular bed and cardiac output. It is important this knowledge be translated from paediatric to adult critical care, transferring not only knowledge and experience but also our specific expertise with aspects of care such as mechanical ventilation and expectations for outcomes. This is an important opportunity for collaboration, one in which the adult critical-care world needs to listen and learn from paediatric cardiac critical care.

Translational change

We are all familiar with the rapid changes occurring with translational biology, particularly the advent of personalised medicine and efforts to match a genotype with the clinical phenotype. Translational learning is also an important evolution, with the training of individuals and teams moving beyond simulation to full immersion laboratories.

For critical care, I believe that *translational engineering* is one of the most important challenges we face. This relates not only to biomedical engineering, whereby we understand the physiological phenotype of the patient within critical care, but it also depends on the introduction of computation and mathematical sciences for data aggregation, structure, and analysis. It also includes the safety science and the means by which we create safe systems through resilience engineering and implementation science. Finally, translational engineering in critical care must also include an understanding of how we can work effectively, and this includes social engineering, understanding human factors, and the ethnography of the environments in which we work.

The impact of "big data" in critical care is a hot topic; however, the meaningful use of this big data is still a challenge. The current state of data utilisation to inform evidence-based practices is fragmented. There is poor customised connectivity with networks and data aggregation to feed user experience, clinical protocols, and treatment algorithms. In research related to big data, data aggregation with customised connectivity and networks has been established,[11] but offline analytics with limited input from clinicians at the bedside do not add to our experience and enhance our management paradigms. The meaningful use of big data requires the aggregation of this data through customised connections and networks with online analytics that directly feed user experience in clinical protocols and then treatment algorithms.

In addition to the continuous physiological data streams available in critical care, the ability to integrate this data with other population-based databases, in effect crowd sourcing knowledge for discovery and innovation,[12] is an emerging concept. Indeed, the aggregation of phenotype with genotype and population databases is providing new avenues for discovery and in many circumstances will replace the gold standard randomised control trial or at least provide important information to inform targeted trials in the future.

A major focus for my research over the past 5 years has been in the meaningful use of continuous physiological data in paediatric critical care. There are important phases to this meaningful use:

- The first is *capturing and storing* continuous physiological data streams. This is relatively easy to do and much more feasible with the relatively low cost of data storage. The frequency with which data is captured and whether or not waveforms are captured along with the digital information are all important considerations, and depend to a large

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extent on the analyses to be undertaken. In general, however, it is important to capture every bit of information that is possible from all devices at the bedside. Conversely, we are limited by vendor-specific devices and monitors, proprietary software that does not allow for data aggregation, and electronic health records that are vendor-specific and can make access to this data difficult. Ideally, we need a vendor agnostic system with continuous data streams from all patients in critical care being stored on a separate server for analysis. It is also important to capture periodic data points such as laboratory data that populate the Electronic Medical Record. I also believe that it is very important we set up systems by which de-identified data can be shared. Although individual research protocols within an institution can inform local practice, we will move our field further much faster if we are able to share data across our institutions to truly understand the physiological phenotypes and how we work. The amount of data that are collected is huge. For example, since June, 2012 at Children's Hospital Boston and April, 2013 at the Hospital for Sick Children in Toronto, all haemodynamic data from patients managed in the cardiac ICUs at these institutions have been captured and stored. Over a terabyte of information has been collected to this point, and one of the concerns is how to access and structure these data. This is a very important initial step, and beyond simply capturing the data there needs to be a platform by which the data can be structured to facilitate analysis. At the Hospital for Sick Children, we now employ a data analyst within the Critical Care Unit to structure the databases to enhance data analysis. At Children's Hospital Boston, they have partnered with Etiometry LLC to develop a data analytics platform that similarly helps unlock these massive data sets.

- *Representation of data*. Too often overlooked, the meaningful representation of data is essential. Clinicians need to interact with the data, overlap waveforms and data points, evaluate trends, undertake calculations, and understand relationships between various physiological signals. I am a co-developer with Dr Mel Almodovar of such a platform, called T3 (Tracking, Trajectory, Trigger tool). This is a flexible and scalable web-based platform that enables enhanced representation of the data and interaction with the data by clinicians.
- The *analysis* of data is critical to enhance our knowledge. There are a number of ways in which data can be analysed from developing trajectory indices to algorithm development by data modelling. An important value of big physiological data sets is the ability to describe physiological phenotypes and ranges of "normal" for various physiological variables in relationship with both disease and procedures; too often we rely on normative data for establishing data ranges and yet many of our patients do not operate within the normal range of healthy population. The development of early warning systems within critical care is possible with trajectory indices; one such index that we have been working on is the Stability Index, which allows clinicians to incorporate select haemodynamic variables into an algorithm that will predict the trajectory of a patient.[13]

A detailed review of the various ways in which data can be analysed is beyond the scope of this lecture; however an important point is that clinicians must remain engaged in this process. Data analysis needs to be online, it needs to have clinician involvement and interaction, and in particular data analysis must include the decisions we make on a daily basis. In the future, critical-care teams will expand to include specialists in translational engineering who will be embedded with clinical teams so that data can be assessed and modelled real-time.

Opportunity

Many years ago, I had the opportunity to listen to Dr Jack Downes from Children's Hospital of Philadelphia address the Society for Pediatric Anaesthesia about the evolution of that specialty. Many will know Dr Downes as one of the fathers of paediatric critical care and paediatric anaesthesia. He described various attributes that helped define the specialty, and these included our contributions and collaborations, discovery and innovation, and development of a body of knowledge.

Within paediatric cardiac critical care, there are many examples of contributions and collaborations across our fields. There have certainly been discoveries and innovation as I outlined earlier in my presentation, and we have developed a body of knowledge as evident by a number of textbooks specifically related to our specialty.

On the other hand, there is another very important component to defining a specialty, and that is our *community and ownership*, and in this regard I wish to specifically refer to the Pediatric Cardiac Intensive Care Society (PCICS). Indeed, the PCICS was born out of an innovation and vision from Dr Chang and others to bring together Chiefs of paediatric cardiac ICUs to enhance collaboration and co-operation. There is no doubt that the PCICS has been successful, particularly holding large conferences such as this 10th International Conference. These conferences have been very successful in bringing people together

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in our field; however, the Society itself is now at a critical juncture and it is time to evolve. We need to be an inclusive and interdisciplinary Society, with a stronger business model. With this in mind, the Board hired a new management company (Ruggles Service Corporation) to manage day-to-day operations, membership benefits, and develop a new interactive website that will provide great value for all the members.

To really move forward, however, we needed to change the structure of the Society, and to do so we needed to change the Code of Regulations. I am very pleased to announce that the Board of the PCICS and its members have voted to amend and restate our Code of Regulations in three important areas:

- There will be one membership category. All members will have voting rights, including non-physicians such as nursing and allied health professionals – that is, we have removed the associate member description. All members will be treated equally.
- The Board composition has been changed: the total number of Directors on the Board will remain at 16, but eight will now be medical and eight will be nursing/allied health members. The Directors will serve 4-year terms, and voting will be for eight members on a staggered 2-yearly cycle.
- Finally and most importantly, we have created two new positions, an Executive VP Medical and an Executive VP Nursing/Allied Health. The Executive VPs will serve 4-year terms and will alternate being the President of PCICS. Our next President from May, 2015 will be Dr Paul Checchia, but in May, 2017 for the first time a nurse will be the President of PCICS. This is an important and natural evolution of our society. It heralds a new era in which there are no boundaries between professions, rather the PCICS will be truly interdisciplinary and we can advance paediatric cardiac intensive care across our fields and institutions.

The Board of PCICS has also approved a number of very important committees, and it is through these committees that the work will be done for our Society. These committees include programmes and meetings, education and training, connections, quality, research and international collaborations. All members can participate in these committees and we expect new innovations and new ideas to emerge from these interdisciplinary committees that will help change our field in the years to come.

Therefore, the value of PCICS is more than connections and collaborations. It will be truly interdisciplinary in which boundaries are blurred between professions and we will create an environment in which we can share ideas, problems, and solutions. This will impact the way in which we practice. For example, we should be able to share practices, quality and safety expectations, as well as create opportunities for accredited training and education and research and advocacy for our fields.

Finally, a very important aspect that we need to examine and improve upon is our ability to partner with and support other organisations and regions across the world. With this in mind, PCICS is partnering with the Working Group on Paediatric Cardiac Intensive Care of the Association for European Paediatric Cardiology and the European Society of Paediatric and Neonatal Intensive Care in the 4th European Conference on Pediatric and Neonatal Cardiac Intensive Care to be held in Montreux, Switzerland, in September, 2015. Similarly, PCICS will have an important and prominent role in the planning for the 8th World Congress in Critical Care to be held in Toronto in June, 2016.

I have huge optimism as I look towards the future. I am excited about the era of medicine and in particular paediatric cardiac critical care on which we are now embarking. Just as there was a wave of development and innovation over 20 years ago at the birth of our specialty, we are now at a time when technology and medicine are coming together. This will enable us to embed new ways to learn, new means to utilise data in a meaningful way to enhance diagnosis and management, open up new avenues for discovery and innovation, and develop new partnerships and teams. Together, we have to leverage this opportunity. It will make us think and learn different, we will work different, but we will make a difference.

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Conflicts of Interest

Peter C. Laussen is a co-inventor of the Tracking Trajectory Trigger tool (T3). The license for T3 is owned by the Boston Children's Hospital, and Dr Laussen is eligible for a proportion of royalties generated from T3. Peter C. Laussen is a member of the Scientific Advisory Board of Etiometry LLC, but receives no remuneration in this role.

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