Respecting different perspectives
11th National Paediatric Bioethics Conference
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The Royal Children's Hospital Melbourne

Abstracts

(In program order)

Day 1 Wednesday 4 September

Session 1: Negotiating diverse cultural and religious differences in a paediatric hospital

Prof Abraham Steinberg – *refer Page 5 of Conference program*

Session 2: Respect *and* disagreement

Medical decisions for children where separated parents are not in agreement

Donna Cooper, Senior Lecturer, Member Australian Centre for Health Law Research, Queensland University of Technology

Select publications articles and papers at:

http://eprints.qut.edu.au/view/person/Cooper,_Donna.html

text: A Harland, D Cooper, Z Rathus and R Alexander, Family Law Principles (2nd ed, Lawbook Co., 2016)

When parents separate they ideally continue to co-parent and make decisions together for their child. However, if they are in high conflict they may not be able to reach agreement on these issues. This paper will look at the intersection of family and health law and discuss the rights of parents after separation to make decisions about their child, termed "parental responsibility" in family law. Generally after separation both parents have the right to have a say in important medical decisions for their child, unless there is a court order that states otherwise. When parents do not agree mediation is usually the first step in the process and then if agreement still cannot be reached one parent will need to make an application to a family court. This paper will look at recent family court decisions that have considered some common health issues for children where parents are in conflict, such as whether a child should be immunised. It will also look at the impact of state domestic violence and child protection orders on parents making decisions for children and being able to be present for medical procedures.

To vaccinate or not: Immunisation disputes in the Family Law system

Sonja Elia & Nigel Crawford, Immunisation Service, The Royal Children's Hospital Melbourne

It is known that Immunisation is one of the most successful public health measures. However, there are still parents who stand firm in their belief that vaccines are unsafe and cause significant side effects. The Immunisation Service at RCH provides advice to families who have questions/concerns about vaccines. This includes both presentations to the Drop-in Centre and paediatrician review at our weekly

Immunisation clinic. But what about when separated parents war over whether to immunise their children, is this just another thing to fight over, or are the ethical issues different?

The ‘No jab, No pay and No play legislations which came into effect on 1 January 2016 and has definitley impacted on Family Court disputes between separated parents in relation to immunisation of children.

From 2014-2019, the Immunisation Service at RCH has encountered 9 cases where immunisation was a major issue in dispute between the parents, or at least was one of the main issues in a larger parenting dispute. The age of the children ranged from 23 months to 11 years. In all of the cases, the mother objected to immunisation of the child. These cases have placed the Immunisation medical and nursing staff in the frontline of the court process, providing scientific and medical evidence for the Family court’s consideration in determining what is in the child’s best interests. Many of our RCH Immunisation staff have had to write reports and some attend court to disuss these issues.

The decision to immunise falls under the scope of ‘zone of parental discretion’ and one parent could simply take a child to be vaccinated, knowing the other parent may well object. This raises ethical consent issues that will vary depending on the age of the child. Our Immunisation service staff are reluctant to carry out vaccination in this instance for fear of court disapproval and potential subsequent repercussions. This presentation will discuss hypothetical cases and explore the ethical considerations of respecting parental differences with regards to immunisation, as well as considering the legal implications.

‘But that’s not what she said to me…’: Whose voice are we hearing?

Dani Gold, Senior Social Worker- RCH Family Violence Project

Jennifer Burn, Senior Social Worker- RCH Family Violence Project

Nicola Watt, Program Manager for Vulnerable Children and Family Violence

Social Work Department, The Royal Children’s Hospital Melbourne

In interactions with patients and their families, our view on what is happening in the family and how to best respond is influenced by what we are told. If we hear only part of a story, we might respond appropriately to that information but our response might not best serve the patient. In some cases, not knowing the whole story can expose the patient to risk such as family violence. Further, members of a team might disagree on the most appropriate response to a family depending upon which part of their story they are aware of. This can lead to conflict within teams, and to patients and families receiving inconsistent messages.

In this presentation, members of the RCH Family Violence project team will present three case studies to illustrate these points, and discuss potential strategies for ensuring teams are aware of all the relevant information and perspectives.

Session 3: Respect *and* parents

Ethical considerations around parents' decisions to choose blended food for tube feeding their child

Dr Heather Gilbertson, Nutrition and Food Services, **Bernadette O'Connor,** Director Allied Health

Kerryn Coster and Rachael Martin, Nutrition and Food Services

The Royal Children's Hospital Melbourne

The RCH Home Enteral Nutrition (HEN) program currently supports around 580 families. This program provides nutritionally complete commercial feeds and consumable equipment every month, as well as regular dietetic reviews for nutritional and growth monitoring.

There has been a growing demand/phenomenon for the use of blended/pureed foods rather than using a commercial product. Use of pureed food down the enteral tube is not recommended and contradicts best practice guidelines as outlined by DAA and AuSPEN. The issues of concern are nutritional inadequacy and implications for inadequate growth and development, bacterial contamination and tube blockages.

While it is recognised that some families are choosing to follow these practices at home, specific issues of concern arise when these children require an admission to hospital. The RCH has very strict legislated HACCP Food Safety Programs (FSP) as a class 1 food premises due to the high risk vulnerable child population it services. Our Food Safety Policy stipulates that the use of a blended/pureed diet administered via an enteral tube is not recommended and CANNOT be undertaken during a patient's admission due to the above concerns, with particular emphasis around food safety risks and inability to store supplies in the ward patient fridge as per our food safety program.

This poses an ethical dilemma with many questions – Why are parents choosing to do that? Who does it benefit? When does parental practice override hospital safety procedures? Is this growing phenomenon due to 'our' inability to educate parents about how to integrate enteral feeding of their child into their usual family life? If we did that better, would this issue go away or increase?

The Twilight Zone: On the edge of the Zone of Parental Discretion

Prof Rod Hunt[1,2,4], Dr Trisha Prentice[1,2,3,4]

[1] Neonatal Medicine, Royal Children's Hospital, Melbourne, Victoria, Australia

[2] Murdoch Children's Research Institute, Melbourne, Victoria, Australia

[3] Melbourne School of Population and Global Health, University of Melbourne, Melbourne, Victoria, Australia

[4] Department of Paediatrics, University of Melbourne, Victoria, Australia

The 'Zone of Parental Discretion' (ZPD) can be a useful decision-making tool when families and clinicians disagree about whether a particular treatment is in the child's best interests. It stipulates parents should be free to make decisions about their child's care – even if considered suboptimal – as long as the child does not experience significant harm. Yet judgements about harm are often determined by subjective assessments of suffering, values and beliefs. Furthermore, the ZPD assumes parents are fully informed and understand the implications of their decisions.

In this case discussion we will explore how parental beliefs, attitudes and actions influence clinician judgements about whether life-sustaining therapies remain within the ZPD and whether this is ethically acceptable. We will question how we can provide greater clarity to the boundary between the ZPD and harm in clinical practice.

The following case is fictitious, but all the elements have been drawn from a number of real cases to highlight the complexity regularly faced within neonatal intensive care.

Baby James was admitted to the NICU following preterm delivery at 34 weeks' gestational age. Immediately following delivery, it was recognised James had a number of significant complex anomalies including congenital heart disease, oesophageal atresia with a distal tracheoesophageal fistula, bladder extrophy with ambiguous genitalia. He also had an anorectal malformation that would require an early colostomy to decompress his bowel.

Various sub-specialists were consulted, and in isolation, all of these issues were amenable to multiple staged surgical corrections. However, collectively, it was unanimously agreed by the treating specialists that this constituted an unacceptable burden of intervention; James quality of life would be very poor for his entire life. Withdrawal of life-sustaining interventions was recommended to James's family.

James's parents were Pentecostal Christians. They insisted that 'everything be done' to keep James alive, believing that God would provide a miracle. James's parents were fervent in their prayers for James but appeared overwhelmed and distant from his care.

Should we respect parents' views about which results to return from genomic sequencing?

DF Vears[1,2]

1 Melbourne Law School, University of Melbourne, Carlton, Australia

2 Biomedical Ethics Research Group, Murdoch Children's Research Institute, Parkville, Australia

Genomic sequencing (GS) is now well embedded in clinical practice. However, guidelines issued by professional bodies continue to disagree about whether unsolicited findings (UF) – ie, disease-causing changes found in the DNA unrelated to the reason for testing – should be reported if they are identified inadvertently during data analysis. This extends to a lack of clarity regarding parents' ability to decide about receiving UF for their children. So, to what extent should parents be allowed to decide which results they want to receive when their child is receiving GS to diagnose an existing condition?

To address this question, I compare professional guidelines addressing return of UF in minors. I then use the Zone of Parental Discretion (ZPD) to consider which UF parents should be allowed to choose (not) to receive and examine how well this assessment aligns with professional recommendations.

Assessment of guidelines shows recommendations ranging from leaving the decision to the discretion of laboratories through to mandatory reporting for UF for childhood onset, treatable/preventable conditions. The ZPD suggests that parents' decisions should be respected, even where there is no expected benefit, provided that there is not sufficient evidence of serious harm. Using this lens, parents should be able to choose whether or not to know UF for adult onset conditions in their children, but only insofar as there is insufficient evidence that this knowledge will cause harm or benefit. In contrast, parents should not be allowed to refuse receiving UF for childhood onset medically actionable conditions.

The ZPD is a helpful tool for assessing where it is appropriate to offer parents the choice of receiving UF for their children. This has implications for refinement of policy and laboratory reporting practices, development of consent forms, and genetic counselling practice.

Day 2 Thursday 5 September

Session 4: Breakfast discussion

‘Why don’t they believe us?’ Challenges with medically unexplained symptoms

Presentations to health professionals of young patients with Medically Unexplained Symptoms are very common. When it is clear to the treating health professional that there is no significant medical (“organic”) cause, most parents can be reassured and accept appropriate non-medicalising management. Parents who do not accept such advice and push for more investigation and treatment can be difficult to manage for a variety of reasons.

This discussion will start with an overview of the problem and then present a representative clinical case for discussion. Finally, a proposed model of care will be presented that involves close collaboration with DHHS.

Session 5: Respect *and* religion and cultural values

The Mature Minor, Competence, and Respect for differing beliefs

In August 2018 in Melbourne a 17 year old pregnant Jehova’s witness woman, with a large baby in utero did not consent to the potential administration of blood products during her delivery. The Obstetric team assessed her to be at a higher than normal risk of intrapartum and postpartum complications that could require the administration of blood products to ensure both her and her unborn baby’s safety.

After refusing to consent for such products on religious grounds, the hospital took the case to the Victorian Supreme Court in an attempt to overrule her decision on the grounds that her capacity to make an informed autonomous decision was limited and that her decision was not in her own best interests.

The court ruled in favour of the hospital being allowed legally to administer blood products as a last resort in the case of risk to life or health[i]. In the ruling reference was made to the mothers competence (capacity for autonomous decision making) and her interests. In assessing her competence considerations included her age, maturity, intelligence level and comprehension of the impacts of her decision on both herself and unborn child. Furthermore, considerations of best interest to mother and child were also taken into account.

Dan will discuss and explore the considerations taken into account in this particular case. In addition, he will consider whether there are any significant differences between the way that we perceive and assess competence in the context of medical decisions made based on religious beliefs compared to those made on the basis of other alternative health beliefs.

[1] *Mercy Hospitals Victoria v D1* [2018] VSC 519; BC201808208

Managing family aggression and conflict in the paediatric intensive care unit: ethical challenges and proposed solutions

Dr Shreerupa Basu, Paediatric Intensive Care fellow; The Children's Hospital at Westmead, Sydney

Ms Anne Preisz, Network Manager Clinical Ethics, Sydney Children's Hospitals Network, Sydney

Parents of children admitted in the paediatric intensive care unit (PICU) come from diverse sociocultural and economic backgrounds with variable personalities, values and morals; as is true in society itself. Though truly challenging behaviour may be rare, when manifested it causes significant conflict and moral distress, particularly if it escalates to become threatening, abusive and aggressive. This may cause considerable harm to the child, the health care professionals (HCPs), the unit- and ultimately to the institution and society. Further, PICU itself is a unique environment with a specific model of care that may magnify these challenges. For the PICU team, the prioritisation of family-centred-care can make it difficult to discern what level of behaviour should be tolerated from families who are grief stricken, stressed and fearful. A societal shift towards individual autonomy and shared decision-making, combined with a distrust in institutions such as medicine, has arguably led to an increase in parental expectations of their right to make decisions for their sick child. However, rights have reciprocal responsibilities, and when this behaviour becomes so harmful that the best interests of the child are subsumed in disproportionate parental expectations, embedded conflict may ensue which can impede optimal clinical practice. When staff feel unsafe and unable to uphold their clinical and professional obligations in the workplace, parental authority should be challenged, with firm limits enacted and supported by all levels of the institution. Managing parental expectations, challenging behaviour and recognising communication 'red flags' early in the PICU journey is key. This may allow for risk stratified strategies that assist in mitigating cumulative harms that have future ramifications for all stakeholders but most importantly, for the sick child.

Unexplored bias may undermine respect

Ms Anne Preisz, Network Manager Clinical Ethics, Sydney Children's Hospitals Network, Sydney

Cognitive bias, both implicit and explicit, subconsciously underlies the values and decisions of health care professionals (HCPs), but also of parents when stressed, grieving and fearful about the prognosis of their emergently sick child.

These inherent assumptions are powerful hidden motivators in decision-making and can 'play-out' in unexpected ways in the child and family's health-care journey, particularly if unarticulated.

Heuristic (experiential) bias relates to our two different systems of thinking (fast and slow)[1], and can lead to embedded cognitive dispositions to respond (CDR) which are prevalent, and unknowingly subvert medical decision-making. This is relevant to our current paediatric medical model of shared decision-making and clinical ethics. Entrenched conflict may ensue when the CDRs of clinicians and parents of a sick infant are uninterrogated.

The story of an extremely premature infant referred to our clinical ethics service will illustrate how the aforementioned biases underpin divergent viewpoints and may lead to entrenched dissent.

Baby CC was born at 24 weeks following a traumatic maternal birth experience. She was resuscitated without time for discussion with the parents and transferred to NICU. CC's parents had a mixed cultural background, and as CC battled for survival overcoming respiratory, brain, vision and bowel compromise, it became evident that certain unarticulated biases were driving the clinical decisions of both the family and the clinicians. A joint decision to palliate her following months of ‘active’ treatment caused moral distress for staff. However, as CC rallied in palliative care, her parents had disengaged as they were disillusioned and distrustful of medical teams. Considering a ‘last ditch’ attempt to save CC’s vision led to a clinical ethics consult.

Unpacking the inherent biases of all parties is crucial in order to understand and respect the parent’s autonomy and cultural values, clinician’s viewpoints, and most importantly the welfare of the child itself.

[1] Thinking Fast and Slow; Kahneman and Taversky, 2011

Yarning with Wadja

What is respectful practice in relation to indigenous families coming into a hospital environment? Is it about actions, words, understandings, attitudes, knowledge – or all of these? In this session, we will talk about these questions with staff members of Wadja, the RCH Aboriginal Family Place, and hear their perspectives and experiences, as indigenous and non-indigenous clinicians. We will invite members of the audience to be involved in the conversation.

‘May I have a female nurse, please?’: Exploring the extent to which nurses can adequately provide culturally appropriate care in practice

Patrick Prunster | Registered Nurse[1,2,3]

1. The Royal Children’s Hospital, Melbourne
2. Clinical Ethics Committee – Children’s Bioethics Centre, Parkville
3. Progressive *Chevra Kadisha* Victoria, St Kilda

In the context of an increasingly multicultural and pluralistic society such as Australia, healthcare is envisioned to provide service to all patients and their families in a manner that recognises and protects cultural differences. Acknowledging cultural diversity is important because clinicians need to develop awareness, sensitivity and competency in order to deliver family-centred care. Cultural competence is the ability to engage appropriately and effectively with people across different cultures. The same principles underpinning family-centred approaches to practice and communication are embodied in cultural competence. However, how culturally accommodating can our healthcare provision truly be? Viewed through the perspective of the nursing workforce, this presentation will analyse the interplay of balancing respect for families with staff safety and resources. Drawing on anecdotal case studies from nursing practice at RCH, we will debate cultural healthcare issues such as female modesty; co-sleeping; visitors to a patient and their family; and strict adherence to Jewish Shabbat laws. The discussion will delve into strategies to overcome barriers to providing culturally appropriate yet clinically safe nursing care, including exploring the family’s ideas about the illness and expectations of treatment, and finding a compromise between medical treatment and cultural values.

Session 6: Respect at the end of life

How can policy become reality in children’s palliative care? A realist inquiry

Dr Sarah Mitchell, Warwick Medical School, University of Warwick, Coventry, UK
Prof Anne-Marie Slowther, Warwick Medical School, University of Warwick, Coventry, UK

Prof Jane Coad, School of Health Sciences, Queens Medical Centre Campus, University of Nottingham
Prof Jeremy Dale, Warwick Medical School, University of Warwick, Gibbet Hill Road, Coventry, UK

Background:
There are significant inequalities in the provision of palliative care to children internationally. Specialist Paediatric Palliative Care services, where they are available, tend not to be resourced adequately to provide palliative care for all children who could benefit from it.

Aim:
To understand the child and family experience of healthcare, taking a realist approach to understand how palliative care is delivered most effectively, to which children, and when, leading to policy relevant recommendations.

Methods:
1. Development of a programme theory (PT) through systematic and realist literature reviews
2. 41 serial interviews with 10 children with life-limiting or life-threatening conditions and 21 family members.
3. Four focus groups with children's palliative care professionals.
4. Thematic / realist analysis to describe the hidden mechanisms (M), triggered in certain contexts (C), to produce desired outcomes (O). CMO configurations are used to refine the PT.

Findings:
The delivery of palliative care depends on interpersonal relationships with healthcare professionals (C). Respect for the family and the development of trust are key mechanisms (M), which lead to child and family outcomes including feeling heard and supported (O). Within healthcare organisations, and continuity of care and legitimisation of palliative care as an approach (C) through leadership and role modelling (M) can lead to improved palliative care (O).

Conclusion:
Future service models that place increased emphasis on healthcare outcomes that are most important to children and families could enable policy and practice goals in palliative care to be achieved more effectively.

What does it mean respecting a child at the end of life: A Bioethics point of view

Stefania Langhi, PhD student, University of Milan

At the end of life several treatments that are administered routinely lack medical indication and may cause significant harm to patients. Medical indication is defined as the appropriateness of a therapeutic or diagnostic measure in the patient's concrete situation.

Among the reason of the overtreatment is fear of the death and the entrenched traditions of life-saving; activist medicine pushes physician to act rather than withhold and to continue a non – beneficial treatment rather than stop it and accept the impending death. The debate over the overtreatment highlights that there is a lack of awareness of the proper decision-making process governing medical action.

When a treatment lacks medical indication, the term "medical futility" is often used.

In order to ascertain the presence or absence of medical indication, three simple questions need to be answered:

1) What is the goal of the proposed measure?

2) Is this goal realistically achievable?

3) Does this goal entail a real benefit for the patients?

The question 3 represents the intuition that not every treatment possible is effective and also beneficial to the patient and thus meaningful. Some treatment measures may do more harm than good. To answer this question, it is necessary to apply the intended goal of care to the concrete situation of the individual patient and to consider both the probability of success and the foreseeable impact of the treatment on the patient's quality of life.

Medical indication means that parent's shouldn't be allowed to refuse treatments of likely benefits for a child or to demand a treatment that imposes a significant burden without benefits. Parents can't have a final say in medical decision but nor can physician, so if there is a dispute that can't be resolved between the two parts, it leads to a legal process. But an imposed decision not adequately explained isn't easily acceptable, it generates conflict and is not ethically respectful of the parts involved. This is the case in which the presence of a clinical ethical consultant aided by scientific knowledge of independent physicians can help in finding a mediation or in explaining why a choice has been done.

What is the value of a 'peaceful' death? And to whom is this valuable?

James Cameron, Melbourne Law School, University of Melbourne

Decisions about whether to withdraw or withhold life sustaining treatment often involve consideration of how the child will die. For some, it is preferable to allow a fast and medically controlled death that may be perceived as 'peaceful'. For others, maintaining human life is of central importance and the manner of one's death is of limited relevance. The relative weight given to a 'peaceful' death in these considerations is informed by cultural and religious views.

This study reviewed relevant case law in Australia, England and Wales to identify trends in substitute end of life decision making for children. These trends were then examined through two ethical theories, value theory and the sanctity of life, to explore how the trends accommodate different views.

A clear trend was identified in the 31 cases analysed favouring a relatively fast and controlled death for a child over attempts to prolong the child's life for as long as possible. This trend appears to reflect a preference for a value theory approach that identifies a 'peaceful' death as a benefit and a rejection of sanctity of life arguments that suggest the priority should always be maintaining life.

Notions of a 'peaceful' death are problematic and reflect particular cultural views. But a parent also does not have a right to impose their views onto their child at any cost. The focus should remain on ensuring the child is comfortable whilst they are alive, yet incorporate parent's views in order to prevent unnecessary distress about the manner of their child's death.

Respecting families' cultural and religious beliefs and practices – going too far or not going far enough?

Dr Sid Vemuri, Consultant in Paediatric Palliative Medicine, Victorian Paediatric Palliative Care Program**;**
Ms Emmelina Finighan, Clinical Nurse Consultant, Victorian Paediatric Palliative Care Program**;**
Dr Kevin Wheeler, Neonatologist, The Royal Children's Hospital, Melbourne;
Dr Bennett Sheridan, Paediatric Cardiologist - Ventricular Assist Devices, Cardiac Intensive Care Specialist, The Royal Children's Hospital, Melbourne, Clinical Senior Fellow, The University of Melbourne, Research Associate, Murdoch Children's Research Institute

Baby H was the fifth child born to Lebanese-Australian parents, and had an antenatal diagnosis of complex congenital heart disease and trisomy 21. He was born at term but small for his gestational age at only 1.58kg, and was transferred to the Royal Children's Hospital on the same day for further cardiac evaluation. Postnatal evaluation confirmed inoperable hypoplastic left heart syndrome, mitral valve stenosis, aortic coarctation and multiple ventricular septal defects.

Baby H's parents hopes for a possibility for surgery of longer term survival, however, there was a unanimous decision from the cardiac surgical team that a staged repair would be futile, and that no palliative surgical options were available. There was a strong recommendation for non-operative comfort care only. In time, the family agreed to prioritise comfort care only and accepted that Baby H would have a shortened life of days to weeks.

The family and treating team shared the goal of provision of comfort, and end of life care at home. However, the family requested ongoing provision of prostaglandin (which was provided intravenously and had been well tolerated since birth). His mother drew on their Islamic faith, recognising that while Baby H would have a shortened life, he was not actively dying currently (breathing and feeding without support). As such, they viewed prostaglandin as prolonging his life rather than prolonging his death and could not accept cessation of this intervention at this time. During their extensive counselling in the three-week admission, they had accepted a limit of two attempts to re-site an intravenous cannula whilst in hospital, and recognised that at home, this re-site would not be possible.

Prostaglandin infusion is usually ceased after there is a decision not to proceed with surgical intervention. Theoretically, intravenous prostaglandin could be provided at home using a syringe driver, much like other continuous infusions used by the palliative care team. Furthermore, there is some literature describing the use of oral prostaglandin for long-term use in newborns with duct-dependent congenital heart disease awaiting cardiac evaluation outside Australia.

Question:

How does provision of life-prolonging interventions usually used as a bridge to active intervention (such as administration of prostaglandin) fit with a palliative approach to care for a newborn with inoperable duct-dependent congenital heart disease?

Singh Y, Mikrou P. Arch Dis Child Educ Pract Ed 2018;103:137–140. doi:10.1136/archdischild-2017-313654 (link)

Session 7: Respect *and* the young person

“Doing what we have to do”: Giving school immunisations to young people with disabilities

Ms Jenny O’Neill[a,b,c], Dr Margie Danchin[b,I,j,k], Dr Giuliana Antolovich[a,c], Dr Sally Lima[e,g,h], Prof Fiona Newall[b,d,e,f,g]

Affiliations:

a Department of Neurodevelopment and Disability, The Royal Children’s Hospital, Melbourne

b The Department of Paediatrics, The University of Melbourne, Melbourne

c Developmental Disability and Rehabilitation Research Group, Murdoch Children’s Research Institute, Melbourne

d Department of Haematology, The Royal Children’s Hospital, Melbourne

e Nursing Research, The Royal Children’s Hospital, Melbourne

f Clinical Haematology Research Group, Murdoch Children’s Research Institute

g The Department of Nursing, The University of Melbourne, Melbourne

h Clinical Learning and Development Unit, Bendigo Health, Victoria

i Department of General Medicine, The Royal Children’s Hospital, Melbourne

j Vaccine and Immunisation Research Group, Murdoch Children’s Research Institute, Melbourne

k The School of Population Health, The University of Melbourne, Melbourne

Government-funded adolescent immunisations are offered to secondary students in Victoria through the School Immunisation Program. Currently the scheduled adolescent immunisations are: the diphtheria/tetanus/pertussis booster (dTPa) and Human Papillomavirus (HPV) vaccine, at 12 to 13 years, and the Meningococcal ACWY at 15 years. The School Immunisation Program includes specialist schools which enrol students with disabilities. The reality of administering this program in a school setting to young people with disabilities is ethically challenging, with issues of consent and assent, conflicting views on the role of restraint, and tensions between respecting a student’s autonomy and acting in the best interest of the health of the child. There is currently no ethical guidance available for schools or immunisation teams in immunising young people with disabilities, and no research in this area. This presentation will use an interactive case study, based on findings from a larger PhD study, to explore these issues in the context of a child with intellectual disability refusing immunisations at school. The issues raised will highlight the need for public health programs and policies to consider ethical issues, beyond those that are present in mainstream populations.

Differing perspectives of RCH clinicians and their adolescent patients regarding fertility counselling in transgender health care

Timothy Lai[a], Dr Rosalind McDougall[a], Dr Debi Feldman[b,c], Dr Charlotte Elder[b,d,e], Dr Ken Pang[b,c,f–h]

[a]Melbourne School of Population and Global Health, University of Melbourne, Parkville, VIC, Australia
[b]Royal Children’s Hospital, Parkville, VIC, Australia
[c]Murdoch Children’s Research Institute, Parkville, VIC, Australia
[d]Austin Hospital, Heidelberg, VIC, Australia
[e]Mercy Hospital for Women, Heidelberg, VIC, Australia
[f]Department of Paediatrics, University of Melbourne, Parkville, VIC, Australia
[g]Department of Psychiatry, University of Melbourne, Parkville, VIC, Australia
[h]The Walter and Eliza Hall Institute of Medical Research, Parkville, VIC, Australia

Transgender people undergo processes of social, medical, and surgical transitioning to align their external selves with their internal gender identity. However, as a part of medical transition, gender-affirming hormone therapy may have long term negative ramifications for fertility. As a result, international clinical guidelines all recommend counselling young people about this risk of hormone therapy and their options for fertility preservation prior to commencement of gender-affirming hormones.

However, these recommendations provide little actual guidance to clinicians on what to say or recommend to patients, and differences in knowledge and attitudes may lead to clinicians adopting different approaches, routines, and goals in the fertility counselling they provide. Consistent with this, published rates of fertility preservation uptake vary considerably internationally, with some centres reporting rates as low as 0% and others as high as ~40%.[1-3]

At the Royal Children's Hospital (RCH), the rates of fertility preservation uptake are among the highest in the world, but the reasons for this are unclear. To better understand how clinicians and young people at the RCH experience and make decisions around fertility counselling and fertility preservation, qualitative semi-structured in-depth interviews of both RCH clinicians and patients were conducted. These interviews explored not only clinician fertility counselling practices, concerns, and challenges, but also patient family plans, experiences of fertility counselling, and decision making about fertility. Data was analysed using inductive content analysis.

In this presentation, I will present our initial findings about clinicians' and young trans peoples' experiences of fertility counselling. The implications of these findings for transgender adolescent health care will be discussed with recommendations for best practice clinical guidelines for fertility counselling in this field.

References

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3. Chung HE, Cooper C, Telfer M, Pang K. High rates of fertility preservation utilization among transgender youth assigned male at birth. [Not Yet Published].

Challenges of Transitional Autonomy: Perspectives from Critical Care

Dr Shreerupa Basu, Paediatric Intensive Care Fellow, The Children's Hospital at Westmead, Sydney Children's Hospital Network

Dr Stephen Brancatisano, General Paediatric Registrar, The Children's Hospital at Westmead, Sydney Children's Hospital Network

Adolescent patients typically transition between paediatric and adult care services between the ages of 16 and 18. This period reflects both transition to adult physiology and a cognitive transition, as patients become recognised as autonomous young adults with the independent capacity to consent. A series of touchstone cases from the Paediatric Intensive Care Unit (PICU) highlight challenges in this transitional period and suggest that paediatric services typically ascribe greater value to family centered care and collective decision-making. This contrasts with adult care where autonomy is commonly enshrined as the core tenet of medical decision-making. In the first case, a 17 year old with anorexia nervosa was referred to PICU for sedation and feeding pursuant to a legal order. It was recognised that in mere months, at age 18, the proposed treatment approach would likely differ substantially. In the second, a 16 year old of superior intelligence with a profound physical disability was treated with protracted intensive care for respiratory deterioration. Though able to form and express her views on continuing treatment, she was a limited participant in such discussions and decision making was deferred to her parents. In the third, a 17 year old underwent two solid organ transplants, with formal consent for both procedures given by her parents only. Prior to the second transplant, her expressed wish to die was rationalised by treating teams and family as a result of her difficult medical course. By highlighting genuine differences in clinical and ethical approaches take by paediatric and adult service providers, these cases identify issues that health care workers on both 'sides of the fence' should be mindful of in ensuring they continue to deliver best ethical and medical care.

Respecting the child- what does this mean in theory and in practice?

Clare Delany, Children's Bioethics Centre

Jessica Tascone , **Sophie Karavaras**, **Olivia Larkens,** Trudi Spence, Child Life Therapy

The Royal Children's Hospital Melbourne

Respecting the child- what does this mean in theory and in practise. This presentation will discuss what respecting the child means in the context of the healthcare setting. We will review the literature from an ethics and child life therapy perspective and discuss findings. A variety a cases studies will be presented examining how this theory translates into practise, with examples of what has worked well and where grey zones arise. A summary will be provided with tips and strategies for clinicians which can be implemented into their own practise.

Day 3 Friday 6 September

Session 8: Respect *and* the clinician

The Monash experience of the first two years of Schwartz Rounds: A forum to support respectful communication between hospital staff

Dr Katie Moore, Paediatric Oncologist, Monash Children's Hospital.

Dr Bronwyn Sacks, Consultant in Paediatric Palliative Care, Monash Children's Hospital and The Royal Children's Hospital, Melbourne

Schwartz Rounds are practised in over 400 institutions across North America, the UK, Ireland, New Zealand, and now also in Australia. In the words of the Schwartz Centre for Compassionate Care(1), they are a forum where healthcare providers are encouraged "to openly and honestly discuss the social and emotional issues they face in caring for patients and families. In contrast to traditional medical rounds, the focus is on the human dimension of medicine."(2) . "They provide a 'counter-cultural' space that differs from the protocol-driven, outcome-orientated healthcare environment that values emotional stoicism."(3) Their purpose is to promote empathetic communication between staff, with the ultimate goal of improving compassionate care to patients and their families.

Monash Health instituted Schwartz Rounds in 2017 across all campuses of the organisation, including Monash Children’s Hospital. We have collected participant responses at every round since then. We propose to present an overview of Schwartz Rounds, our experience in setting up the Monash program and our cumulative data on the impact of this initiative.

Our experience is that Schwartz Rounds break down individuals’ perceived sense of isolation at work, legitimise discussion of the reflective and personal aspects of healthcare (as opposed to problem-solving, clinical issues), encourage safe expression of vulnerability, flatten traditional hierarchies and stimulate insights into the similarities between disparate professional disciplines.

We will make an argument that over time, the Schwartz approach mitigates against problematic conflict between individuals and teams via promotion of respectful communication and is therefore supportive of ethical professional relationships.

1. https://www.theschwartzcenter.org
2. https://www.theschwartzcenter.org/supporting-caregivers/schwartz-center-rounds/
3. Maben, J. Taylor, C. Dawson, J. Leamy, M. McCarthy, I. Reynolds, E. Ross, S. Shuldham, C. Bennett, L. Foot, C. (2018) A Realist informed mixed methods evaluation of Schwartz Center Rounds in England. Final NIHR HS&DR Report.

Understanding the Unimaginable – the stories we tell to help us work with cases of suspected child abuse

Danielle Coughlan, Shanti Petronzio and Jessica Windridge

Senior Social Workers, Social Work Department, The Royal Children’s Hospital, Melbourne

When children present with suspected non-accidental injuries (NAI’s), a range of healthcare staff become involved in assessing the nature and cause of the child’s injury. Parents of children with suspected NAI’s can have highly plausible through to highly improbable explanations for how the injury occurred. They may become upset and defensive should the idea of NAI be raised. For staff (and at times for parents), a common feature of these scenario’s is ‘cognitive dissonance’; the discomfort experienced by a person when confronted with facts that contradict their beliefs, ideals and values.

In this presentation, we will discuss a phenomenon we have noticed in our social work practice where clinicians try to resolve this dissonance and attempt to make sense of the contradictions observed in suspected NAI presentations. We have noticed how practitioners build a story around these cases which may include a plot, a villain, and a victim.

We believe these stories perform three useful purposes:

- Telling the story helps to make visible ethically important and challenging moments, including how staff characterise those involved;
- Telling and comparing stories helps to share (and debrief about) the dissonance, the trauma and the emotions involved in this work;
- Telling the story helps staff share their ideas about cause, while still respecting possible different views from the patient, patients family, RCH staff and outside organisations

This presentation will draw strongly on case studies and encourage audience participation to look at the steps involved in the creation of these stories and how this process can help staff to understand and manage these cases.

Caring for individuals who are intersex/ have a difference of sex development, and their families

C. Hanna[1,2]; SR. Grover[1,2,3], M O’Connell [1,2,3]

[1]Royal Children’s Hospital, Melbourne. Victoria, Australia

[2]Murdoch Children’s Research Institute, Melbourne. Victoria, Australia

[3]University of Melbourne, Melbourne. Victoria, Australia

“Is it a boy or a girl?”; “Can I have children?”; “Genital surgery without consent is genital mutilation!”; “What does a malignancy risk mean?”; “He needs to be able to stand up to wee”.

The clinical care of individuals with intersex variations / Differences/Disorders of Sex Development (DSD) can be complex. In particular, when these individuals are diagnosed as babies, any treatment must consider the individual’s rights (including the rights of their future self), the parental rights and the medical evidence.

Diagnosis of individuals with DSD has improved in the last decade due to advances in biochemical, histopathological and genetic testing and technology.

Clinical management for children with intersex variations at our centre has evolved with the establishment of a multidisciplinary team (MDT) comprising surgeons, physicians, allied health professionals, scientists and bioethicists. These meetings, which began over 20 years ago were initially relatively informal. They are now are more formally structured. Decisions around clinical care and family perspectives, possible medical / surgical interventions and ethical issues are discussed and reviewed at these monthly MDT meetings.

In 2016, the role of clinical coordinator at our centre was introduced, aiming to assist with patient care coordination, coordination of the clinical MDT and to develop psychosocial resources for families.

This role has expanded into advocating for the transparent discussion of the many perspectives surrounding the implications of diagnosis, medical interventions, clinical evidence / or lack of, lived experiences of adults, human rights considerations, parental values, cultural and spiritual values.

The pathway from the appearance/identification of a DSD in an individual through the critical decisions involved in the provision of health care for a person with a DSD diagnosis is complex and challenging. The DSD co-ordinator is one of the key MDT members trying to balance the diverse inputs to ensure the optimal outcomes. This presentation will explore ways in which we navigate these sometimes dissenting points of view.

Session 9: Respect *and* new technologies

Germline gene editing, reasonable precaution, and the limits of parental autonomy

Julian Koplin [a,b] & Christopher Gyngell [a,c]
Affiliations:

[a] Biomedical Ethics Research Group, Murdoch Children’s Research Institute

[b] Melbourne Law School, University of Melbourne

[c] Department of Paediatrics, University of Melbourne

The recent development of gene editing technologies such as CRISPR-Cas9 has revolutionised genetic engineering. Gene editing techniques are more efficient, more precise, and less expensive than older methods of genetic modification. This has opened up a range of new applications for genetic engineering, the most controversial of which is the use of germline gene editing (GGE) in human reproduction. While it is widely agreed that GGE is currently too unsafe for human trials, this is liable to change as the technology improves.

In this presentation we consider the conditions under which prospective parents should (not) be permitted to decide whether to modify their offspring using GGE. In doing so, we show how the precautionary principle can help us identify forms of GGE that are particularly problematic. We close by describing which forms of GGE it might eventually be permissible to offer to prospective parents, and which should remain unavailable.

Going Home. Understanding the value of home in the management of children requiring long-term mechanical ventilation from the perspective of healthcare professionals

Juliette Jeffreys[1], Lynn Gillam[2], John Massie,[1,2] Department of Respiratory Medicine[1] and Children's Bioethics Centre[2], The Royal Children's Hospital

Technological advances have made it possible for technology-dependent children to live at home rather than a hospital setting. One sub-population of technology-dependent people are children dependent on long-term (mechanical) ventilation. These children are medically complex and socially vulnerable and require much input from the healthcare team. For children with chronic diseases in general, being at home has been seen to improve developmental outcomes and restore family life. Furthermore, home-based ventilation care reduces costs to the healthcare system. However, caring for a technology-dependent child in the community has profound emotional, physical and financial implications on the lives of patients and their caregivers. Caring for a ventilated child is reported as more stressful than for children with other disabilities or chronic diseases. Further evidence is needed to understand what it is about being at home that is the best place for children dependent on long-term ventilation.

Despite guidelines from professional bodies, there are large regional differences in how patients are selected for ventilation and managed thereafter. There is minimal literature focusing on the practical and ethical decision-making process in *individual* cases.

The purpose of this study is to understand the what "going home" means for children requiring long-term ventilation and consider the decision-making processes involved in selecting these children. We will report the results of our qualitative semi-structured interview of medical and nursing staff in Victoria and NSW. Our interviews consider the experience of staff caring for children on long-term mechanical ventilation, experience of families and caregivers of children on long-term mechanical ventilation, the decision-making process, and the place of home for these children.

Session 10: Respect – an exploratory ethical dialogue

Prof Lynn Gillam, Clinical Ethicist and Academic Director & **Prof Clare Delany,** Clinical Ethicist, Children's Bioethics Centre, The Royal Children's Hospital Melbourne - *Refer Page 6 of Program*