Neonatal Palliative Care: Issues in Ireland

E MOLLOY
NEONATOLOGY
NMH, RCSI, UCD, OLCH

Overview

- Overview
  - Neonatal Palliative Care
  - Congenital anomalies
  - Irish perspectives: survey
  - Home care
  - Education
  - Neonatal Organ donation
  - Future plans

Introduction

- Supporting parents during the bereavement of a child is an important part of neonatal care
  - Often overlooked in neonatal medical training
- Despite evidence that complex grief reactions can occur with limited support
  - Kersting A & Wagner.Clinical Neuroscience 2012
- Multidisciplinary care beneficial
  - involving palliative care and bereavement teams antenatally in cases with a diagnosis of fatal foetal anomaly
    - Balaquer A et al BMC Paediatric 2012

Paediatric Palliative Care Services

Relationship between palliative care and treatments aimed at cure or prolonging life	
	As the illness progresses the emphasis gradually shifts from curative to palliative treatment.
	Highly technical invasive treatments may be used both to prolong life and improve quality of life alongside palliative care, each becoming dominant at different stages of the disease.
	No cure is possible and care is palliative from the time of diagnosis.
	At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.
Key: ☐ curative ■ palliative	

Together for Short Lives

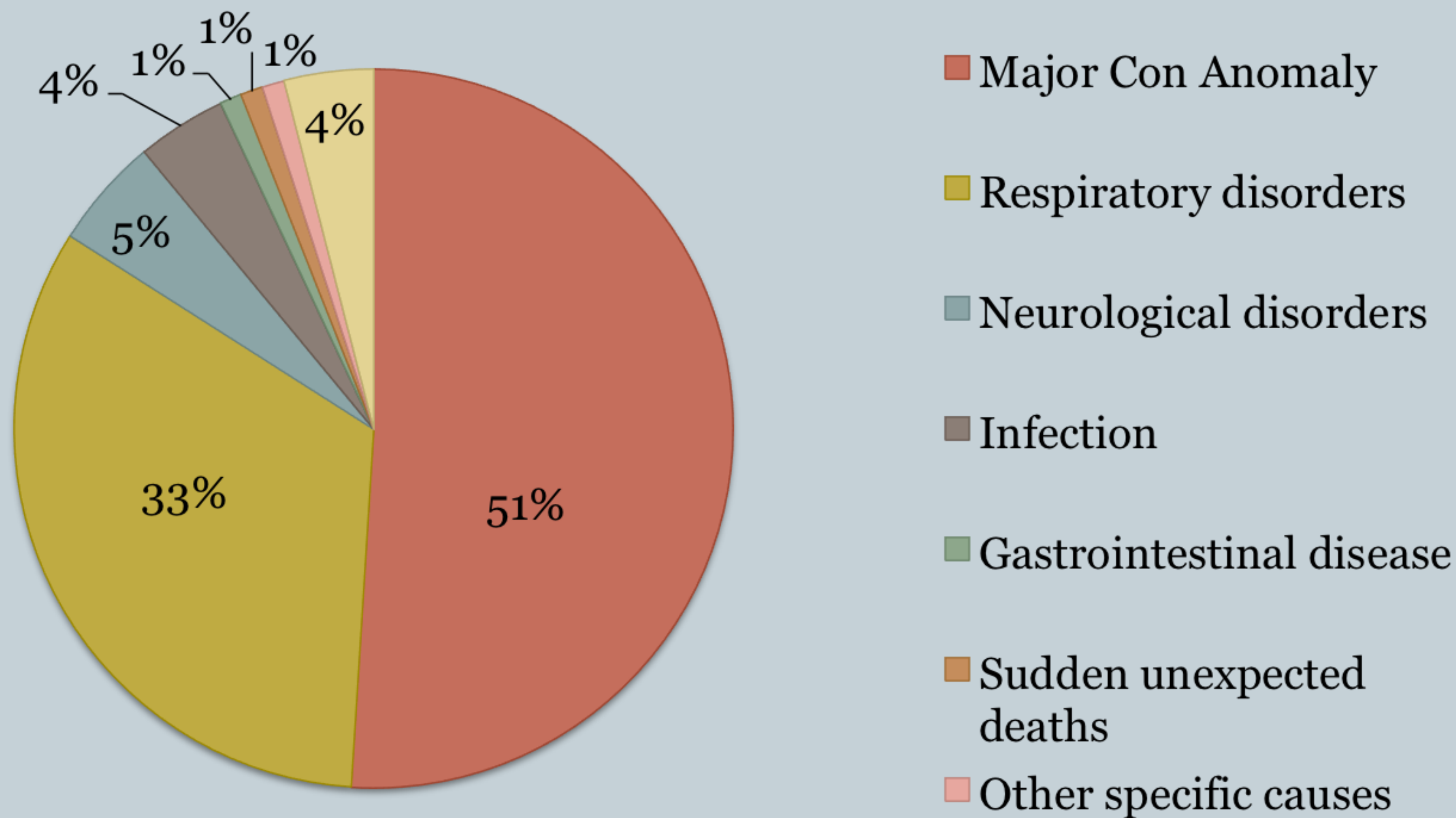
Perinatal Palliative care in Ireland

- Ireland is unique
  - Legislation on termination of pregnancy
  - Increased congenital anomalies
  - Cultural

- 5 large maternity centres ~9000 births pa
  - All-Ireland: 50-60,000 births pa

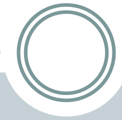
- ~ 500 deaths perinatal

Early neonatal deaths : Perinatal mortality in Ireland, NPEC, 2011



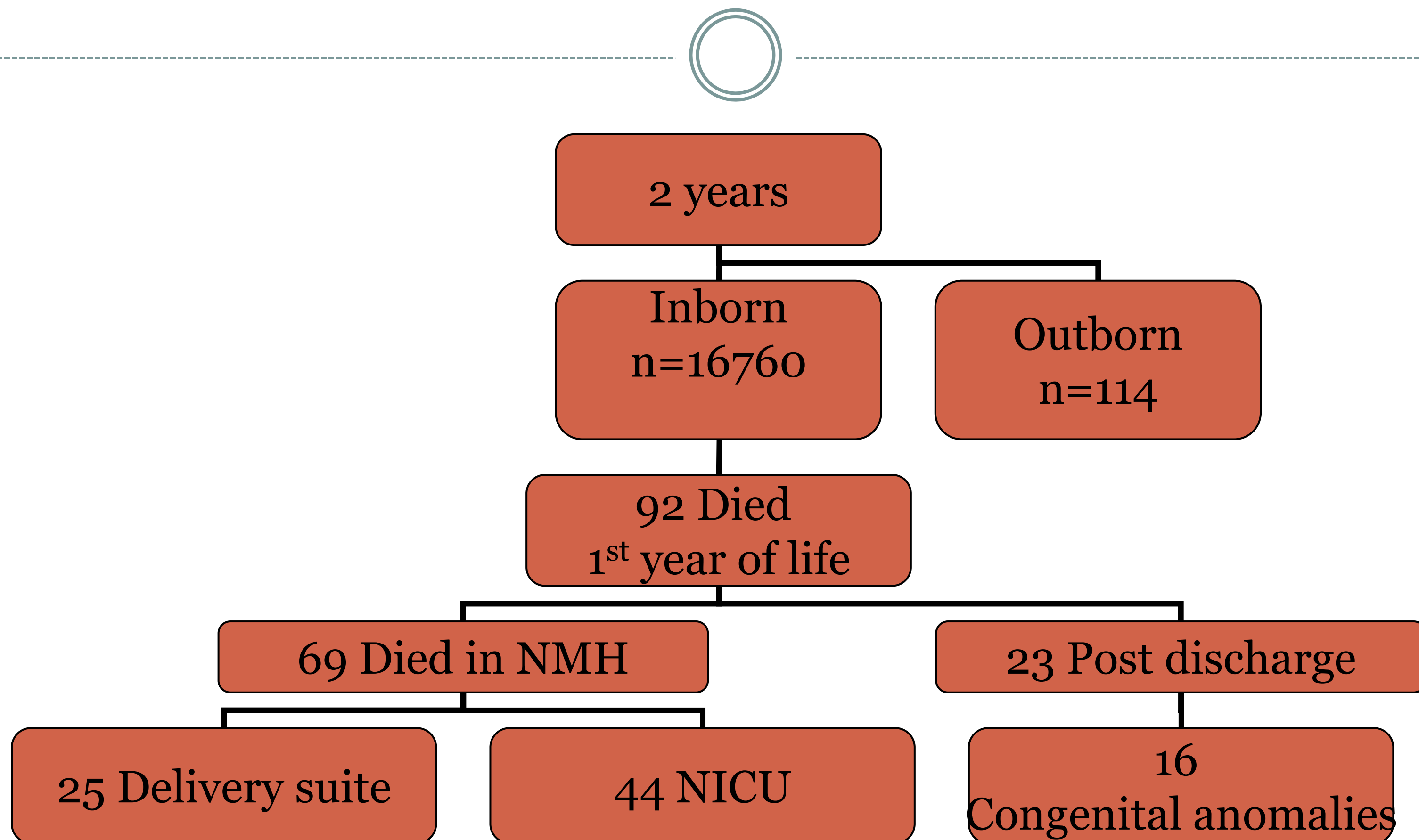
Kurinczuk et al., 2010; Major Con Anomalies ~ 30%, UK

Research Audits Neonatal Deaths



- AUDIT OF CAUSE AND SITE OF DEATH
- NATIONAL SURVEY OF NEO PALLIATIVE CARE
- BEREAVEMENT FOLLOWUP

Overview of Neonatal death in NMH



McHale et al. Death in a Tertiary Irish Maternity Hospital: Causes, Withdrawal of Care and Post-Mortem Examination Rates; SPR Baltimore, 2009

Cause of death

- Prematurity
  - 42/92 (46%)
- Congenital anomalies
  - 41/92 (44%)
- Normally formed >1.5kg
  - 9/92 (10%)

Place of death

- Delivery suite n=25
  - only 1 despite resuscitation
  - 9 had known lethal congenital anomalies
  - 15 were determined pre-viable
- Neonatal intensive care unit (NICU) n=42
  - 12 congenital anomalies
  - 26 extremely preterm infants
  - 4 normally formed infants > 1.5kg.
- Postnatal ward n=2
  - lethal trisomies

    - **McHale et al. Death in a Tertiary Irish Maternity Hospital: Causes, Withdrawal of Care and Post-Mortem Examination Rates; SPR Baltimore, 2009**

Withdrawal of intensive care

- Discontinuation of intensive care offered n=40
  - Intensive care discontinued n=31
    - 30 of whom died
    - 1 of whom survived despite withdrawal.
  - Death in NICU despite continued intensive care
    - 9 infants
- Post-mortem examinations
  - performed in 26/92 (28%) cases.
    despite being offered to all families
- Congenital anomalies accounted for almost as many deaths in the first year of life as extreme prematurity.

Neonatal Palliative Care Practice in Ireland

- NICU & PICU survey
  - n=20; responses n=18
  - Palliative care guideline
    - n=1 in use; n=32 in development
  - Inadequate facilities
  - End of life care in ICU not dedicated family room
  - Side-room for families n=6
    - Frequently used for storage
      - Walsh H, Molloy E, IMJ, 2013

Multidisciplinary team

- Majority of care
  - neonatal nurses, neonatologists, chaplains and social workers.
- Bereavement officer
  - Only 3 units There was no in-house teaching and little bereavement support
- Medication
  - Morphine was the medication of choice for symptom-relief n=12
  - Paracetamol only n=9
- Formal family bereavement followup
  - n=2 only 2
- All respondents felt that a dedicated PC team essential
- 12 suggesting that a paediatric palliative care was essential in collaboration with paediatric palliative care consultant

Survey Summary

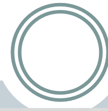
- In Ireland
  - Challenges
    - paucity of specialised paediatric care in palliation
    - prescribing issues
    - support for parents is often dependent on geography

- Solutions
    - Palliative care protocols are important to provide support with end of life decision-making, bereavement and pain management.
    - urgent need for appropriate guidelines, specialist paediatric palliative care posts, improved community support and the establishment of continuing education.

Bereavement, social and medical support in end-of-life neonatal care

- 9,459 babies delivered in NMH in 2011
- 53 neonatal deaths included
- 46(87%) of these were delivered in NMH
- 38(72%) premature <37 weeks

Bereavement, social and medical support in end-of-life neonatal care



Follow up after bereavement

Category	Number (%)
Follow up with bereavement team	41 (77%)
Follow up with MSW	13 (25%)
Follow up with paediatrics	7 (13%)
Follow up with obstetrics	12 (23%)

Results

- 46(87%) died in the NMH
- 5(9%) died in other tertiary referral paediatric hospitals
- 2(9%) died at home
- 37(70%) died in first 72 hours of life

Results

Causes of death

Other 8%

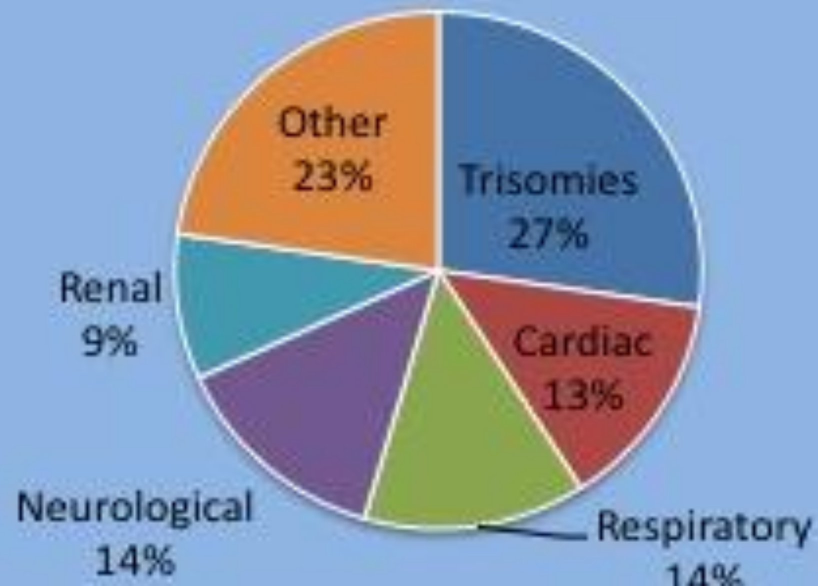
Sepsis 4%

HIE 6%

Prematurity 41%

Congenital anomaly 41%

Results



Results

- 23(43%) post mortems were performed
- Congenital anomalies accounted for 22 (41%). Many of these were antenatally diagnosed
- Palliative care were involved antenatally in 8(15%)
- Outcome:
  - Checklist and repeat followup
  - Anniversaries

Neonatal Life-limiting conditions

- 3 scenarios: BAPM guidelines 2010
  - ELBW on maximum intensive care
    - No response
    - Severe IVH
  - Severe Neonatal encephalopathy
    - Extubated with days –weeks expected survival
  - Major Congenital/Chromosomal abnormality
    - Intervention futile
    - Edwards syndrome/ Major inoperable cardiac anomaly

Extremely low birth weight infant

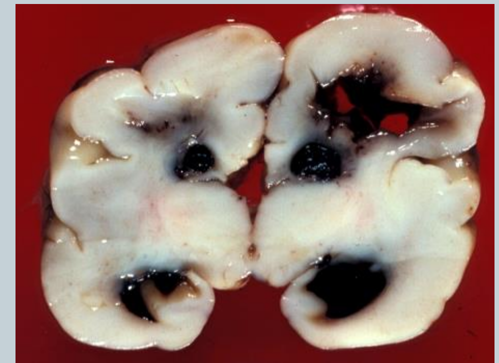
- 24 week twin II
  - Male
  - ANS x 1
    - 2 h
  - PROM 3 weeks
  - IVF
  - Antenatal counselling +++
  - NICHD figures
  - Twin I RIP at 1 hour in DS

- Day 2:
- Honeymoon over

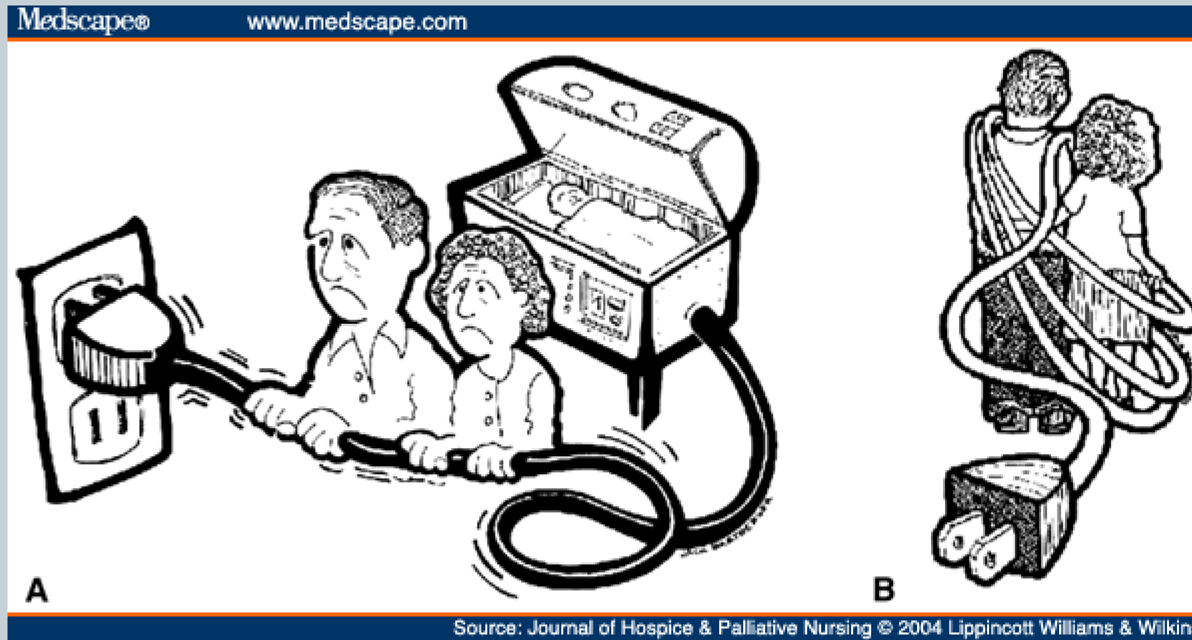
- Deterioration
  - Resp: on NO/ 80% FiO2
  - CVS: 3 inotropes
  - CNS:
    - IVH: Bilateral grade 2=> Grade 3/4

- Parents counselled
  - No increase in intensive care=> at limit
  - Poor prognosis for survival and definite disability

  - Options:
    - Continue with no increased ICU
    - Continue but hold him on ventilator with all family visiting
    - Remove ETT and hold him in parents room



A) "Pulling the Plug" (B) "The Burden"



- Bartberger, J., 2003

Severe Brain injury

- Encephalopathy initially comatose
- MRI profoundly affected
- Extubated as withdrawal of care
- Spontaneously breathing
- Surviving at 24 hours

- Tx Sunshine home
- RIP 6 months of age

Major chromosomal /congenital abnormalies

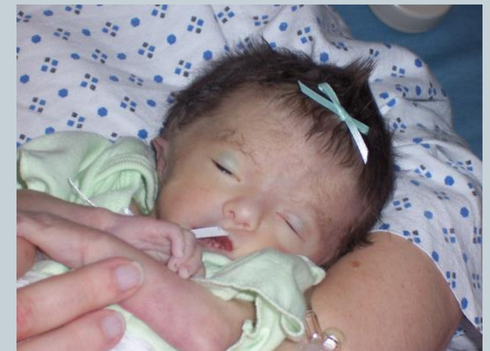
- Trisomy 13
- Complex cardiac anomalies considered inoperable
- Pulmonary hypoplasia

- +/- Antenatal diagnosis

Life-limiting condition: Edwards syndrome/Trisomy 18

- No antenatal diagnosis
- Diagnosis: Clinical features and FISH
- No requirement for ICU
- Large VSD/PDA/Pul HTN
- Bilateral hip dislocation

- Early introduction of palliative care team



Palliative care supports

- Paediatric Palliative care team
  - OLCH/ Community
- Parents room
- Nursing and medical team
- Family followup
- Annual Remembrance Service
- Bereavement counsellor
- Chaplaincy

Home care

- Can we truly offer a place of death in neonatal palliative care?
    - Craig et al 2013, Semin Fetal & Neo Medicine
    - Hospital/Hospice/Home/Garden
- Individualised care
    - Baby's illness
    - Family's needs/Siblings
- Community support
    - Checklist of community support/letters

Education

- Undergraduate
  - n=143 students: BBN: Lecture/peer-role play
  - 77% observed BBN esp during Paediatrics
  - Average self rated competency (score 1-10) increased from 4.26 to 6.61 ($p<0.001$)
    - McElligott F & Molloy E, ESPR,2012

- Postgraduate
  - Hospice Foundation: adapting to Neonatal environment
  - All staff
  - Guideline updates
  - Self care
    - Mancini A et al., 2013,Semin Fetal & Neo Med

Resources

- Paediatric Palliative Care team
- Liaison network
- Jack and Jill Foundation
- Sunshine Home

Neonatal Organ Donation

- Ireland
  - Heart valves: Mater hospital
  - Corneas: no SOP at present
- ADC article
  - DCD
    - Diagnosis of brain death in infancy
- National guideline in development

Palliative care : ideal

- Perinatal palliative care team
  - Community care network
  - National
- Family room
  - Space in neonatal intensive care unit
  - Family room
- Education
  - Health care workers
  - Community care
  - Multidiciplinary
- Research
  - Irish Neonatal Palliative Care interest group
  - Multidisciplinary, collaborative

EXIT

Suitable family environment

Immediate Future

- Environment
  - Family centred care
  - Home care
- Structured national guidelines
  - Antenatal/perinatal and postnatal management
  - Pathways to community care
- Partnership
  - Families
  - Multidisciplinary team
  - Parent support groups

Longer term future

- National registry
  - NPEC
  - Congenital anomalies
    - EUROCAT All-Ireland
- Resource allocation
  - Inequity in Health care
- Advocacy

Thankyou

HELEN WALSH
SHEILA POWER
BEREAVEMENT TEAM IN NMH
PAED PALLIATIVE CARE TEAM, OLCH