Neonatal Palliative Care: Issues in Ireland

E M OLLOY
NEONATOLOGY
NMH, RCS, UCD, OLCH
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

- 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
<table>
<thead>
<tr>
<th><strong>Relationship between palliative care and treatments aimed at cure or prolonging life</strong></th>
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<tbody>
<tr>
<td><img src="image" alt="Diagram" /> As the illness progresses the emphasis gradually shifts from curative to palliative treatment.</td>
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<tr>
<td><img src="image" alt="Diagram" /> 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.</td>
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<tr>
<td><img src="image" alt="Diagram" /> No cure is possible and care is palliative from the time of diagnosis.</td>
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<tr>
<td><img src="image" alt="Diagram" /> At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation comes.</td>
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| 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

2 years

Inborn
n=16760

92 Died
1st year of life

69 Died in NMH

25 Delivery suite

44 NICU

Outborn
n=114

23 Post discharge

16 Congenital anomalies

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

- 41 (77%)
- 13 (25%)
- 7 (13%)
- 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

- Congenital anomaly: 41%
- Prematurity: 41%
- HIE: 6%
- Sepsis: 4%
- Other: 8%
Results

Breakdown of congenital anomalies

- Trisomies: 27%
- Respiratory: 14%
- Neurological: 14%
- Cardiac: 13%
- Renal: 9%
- Other: 23%
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 abnormalities

- 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
  - Multidisciplinary

- **Research**
  - Irish Neonatal Palliative Care interest group
  - Multidisciplinary, collaborative
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