Children with non-oncological life-limiting conditions deserve the same high-quality palliative care as children with incurable cancer

Results of a retrospective case-notes audit

Archana Soman
Consultant Paediatrician

Norfolk and Norwich University Hospitals NHS Foundation Trust

Jenny Lind Children’s Hospital
Aims of the audit

• To determine if all children with LLCs have their palliative care needs assessed, planned and delivered - as per standards set out by Together for Short Lives (TfSL).

• To aid the development of a local guideline and framework (care pathway) to ensure the above happens.
TfSL Core Care pathway for Children with Life-limiting and Life-threatening Conditions

Stage 1: Diagnosis and/or recognition
- Sharing significant news – diagnosis and prognosis
- Liaison with and/or transferring to community services

Stage 2: Ongoing care
- Multidisciplinary assessment of needs
- Child and family care plan/s

Stage 3: End of life
- End of Life plan
- Bereavement support
Methods

• Inclusion Criteria
  • Children who had died as a direct result of a condition/s that is clearly life-limiting, 2011-2015

• Exclusion criteria
  • Sudden/ unexpected deaths even in children with a LLC diagnosis
  • Children whose care was mainly led by another hospital
  • Deaths on the neonatal unit, or within a month of diagnosis of LLC

• Data collection
  • Case notes, electronic databases, M&M minutes
Distribution of main diagnoses

Total: 20
- Oncology: 8
- Severe neurodisability: 10
- Complex congenital heart disease: 1
- Cystic Fibrosis: 1
Prevalence of Life-Limiting Conditions in children in England by Major Diagnostic Group, 2000-2010

- Neurological
- Oncology
- Haematological
- Metabolic
- Congenital
- Respiratory
- Circulatory
- Genitourinary
- Gastrointestinal
- Perinatal
- Other
Age at death

Sex

Norfolk and Norwich University Hospitals
NHS Foundation Trust

JENNY LIND
CHILDREN’S HOSPITAL
Time from confirmation of LLC to death

- < 1mo
- 1 mo – 2 mo
- 2 – 10 years
- 12 – 23 mo
- 2 to 10 years
- > 10 years

Norfolk and Norwich University Hospitals NHS Foundation Trust

Jenny Lind Children’s Hospital
Audit Standards and results

1. There should be an honest discussion with the parent/s of all children with life-limiting conditions when such is identified, in an appropriate setting, and this should be documented in the hospital notes: 100%

   Documented in 19/20: **95%**

   But...discussions about the life-limiting nature hardly documented

   Oncology: ‘no more curative options’
Audit standards and results

2. An initial MDT meeting should be held to assess needs and plan delivery of care: 100%
   
   Result: 17/20: 85% (Onc: 100%, Non-onc: 75%)

3. The MDT should identify a key worker and a lead clinician: 100%
   
   Result: Both clearly identified in 9/20: 45%
   
   (Onc: 87.5%, non-onc: 20%, p = 0.01 )
   
   • One or the other in 9
   • Neither in 2
Audit standards and results

4. The child’s palliative care needs including current and anticipated symptoms should be assessed by the MDT and documented

   Result: 12/20 60%
   (Onc: 100%, non-onc: 33.3%, p = 0.015)

5. Symptom management plans (including roles of clinicians and lines of communication) made

   Result: 13/20 66.7%
   (onc: 100%, non-onc: 41.7%, p = 0.0225)
Audit Standards and results

6. Family structure and psychosocial and cultural needs should be assessed and documented

   Result: 15/20 75%
   (Onc: 100%, non-onc: 58.3%)
Audit Standards and results

7. End of life care plans should be discussed and documented:

a) DNACPR: 13/20 **66.7%** (including 3 that did not engage)  
   (Onc: 100%, non-onc: 41.7%)

b) Place of EoL care/ death: 11/20 **55%**  
   (Onc: 100%, non-onc: 25%)

c) Other wishes and desires: 9/20 **45%**  
   (Onc: 75%, non-onc: 25%)

d) All 3: 8/20 **40%**  
   (Onc: 75%, non-onc: 16.7%, p = 0.0325)
Comparison cancer vs non-cancer

\[ p = 0.01 \]
\[ p = 0.015 \]
\[ p = 0.0225 \]
\[ p = 0.0325 \]
Other observations (1)

Place of death

- All patients
- Cancer
- Non-cancer

- Home
- Hospice
- Hospital

Norfolk and Norwich University Hospitals NHS Foundation Trust

Jenny Lind Children's Hospital
Other observations (2)

• Intensive care: 4 (0 oncology)
  • 1 for 3 weeks
  • 1 for 32 days

• Resuscitation: 4 (0 oncology)
  • 2 prolonged full CPR (one had SUDIC protocol)
  • 2 partial (short of cardiac massage and drugs)
Summary of findings

• Poor documentation – especially of communication of prognosis and lead professional/ key worker.

• MDT assessment and planning incl. end-of-life care planning grossly inadequate – especially in non-oncological LLC

• Clear disparities between oncological and non-oncological LLC
Oncology versus non-oncology

• Often clear demarcation between ‘potentially curable’ and ‘non-curable’
• ‘Futility’ more acceptable a concept given the social and cultural connotations of the ‘C’ word?
• Clear regional palliative care pathway for children with oncological diagnoses
• Limited research suggests that this is reflected in families’ perception of services (Price et al, 2012)
Recommendations/actions

- Care pathway and guideline for MDT management of children with LLCs - written
- Database of CYP with life-limiting conditions
- LLC forum and care coordinator
- Named paediatrician/s for palliative care
- Rolling (annual/biannual) MDTs for all children with LLCs
- Education programme : several completed already
- County-wide clinicians’ group
- Commissioners and acute Trust beginning to engage
References


• NHS STANDARD CONTRACT FOR PAEDIATRIC MEDICINE: PALLIATIVE CARE 2013/14. NHS Commissioning Board (now NHS England)

• Child & Young Person’s Advance Care Plan Policy - April 2011 West Midlands Paediatric Palliative Care Network

