Children in Scotland requiring Palliative Care (ChiSP Study)

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Outline

- Aims/Objectives
- Workstream 1 findings and recommendations
- Workstream 2 findings and recommendations
- Concluding comments
Aims/Objectives

• to develop an evidence base to support and inform planning for children’s palliative care in Scotland
  – to identify the number of children and young people with life-limiting or life-threatening conditions in Scotland;
  – to describe this population in terms of their ages, conditions/diagnoses, geographic locations and ethnicity;
  – to generate evidence on their psychosocial care needs.
Workstream 1

The numbers and characteristics of children and young people with life-limiting conditions in Scotland: findings and recommendations
Definitions

- **Life-limiting conditions** are those for which there is no reasonable hope of cure and from which children or young people will ultimately die prematurely, e.g., Duchenne muscular dystrophy or neurodegenerative disease.

- **Life-threatening conditions** are those for which curative treatment may be feasible but can fail, e.g. cancer.
Methodology

prevalence = \frac{\text{number of individuals with a LLC}}{\text{population at risk}} \times 10000

- Hospital based prevalence
- ‘Complete’ prevalence
- Deaths/place of death
- Aggregate data from CHAS
Stage of Condition

Dying

Deteriorating
- Any emergency ICU admissions
- Discharge from ICU to hospital
- Discharge to normal place of residence (and no death within 28 days)

Unstable
- Emergency inpatient admission lasting two or more days

Stable

28 days before death
Recommendation 1

• More children and young people of ALL AGES in Scotland with life-limiting conditions should have input from palliative care services
Prevalence

CHAS receive ~ 115 new referrals and currently cares for ~ 380 children and young people and their families each year.
Prevalence by Age

Graph showing the prevalence of a condition by age group over different financial years. The graph compares hospital-based prevalence and complete prevalence.
Prevalence by Gender

- Hospital-based prevalence: male
- Hospital-based prevalence: female
- Complete prevalence: male
- Complete prevalence: female

Prevalence per 10,000 population

Financial year:
- 2003/04
- 2004/05
- 2005/06
- 2006/07
- 2007/08
- 2008/09
- 2009/10
- 2010/11
- 2011/12
- 2012/13
- 2013/14
Prev. by Diagnostic Group

Hospital-based prevalence:
- Neurology
- Haematology
- Oncology
- Metabolic
- Respiratory
- Circulatory
- Gastrointestinal
- Genitourinary
- Perinatal
- Congenital
- Other

Complete prevalence:
- Prevalence per 10,000 population

Financial year:
- 2003/04
- 2004/05
- 2005/06
- 2006/07
- 2007/08
- 2008/09
- 2009/10
- 2010/11
- 2011/12
- 2012/13
- 2013/14
Prev. by Health Board

Graph showing prevalence per 10,000 population over financial years from 2003/04 to 2013/14 for different health boards:
- Ayrshire & Arran
- Borders
- Dumfries & Galloway
- Fife
- Forth Valley
- Grampian
- Greater Glasgow & Clyde
- Highland
- Lanarkshire
- Lothian
- Tayside

The graph compares hospital-based and complete prevalence across financial years.
Stage of Condition

- Stable for whole year
- Unstable during year
- Deteriorating during year
- Dying during year

Financial year:
- 2009/10
- 2010/11
- 2011/12
- 2012/13
- 2013/14

% of total
Stage of Condition by Diagnostic Group
CHAS currently cares for ~ 60 children and young people who die each year.
The potential demand for palliative care in the 0-25 year age group outstrips the current provision.
Recommendation 2

• Children under 1 year of age should be seen as a priority group for input from palliative care services
Prevalence by Age

Prevalence per 10,000 population

- Under 1
- 1 to 5
- 6 to 10
- 11 to 15
- 16 to 20
- 21 to 25

Hospital-based prevalence

Financial year: 2003/04 to 2013/14

Prevalence per 10,000 population

Complete prevalence

Financial year: 2009/10 to 2013/14
Stage of Condition by Age

Graphs showing the stage of condition by age and financial year from 2009/10 to 2013/14:

- Stable for whole year
- Unstable during year
- Deteriorating during year
- Dying during year

Legend:
- Under 1
- 6 to 10
- 1 to 5
- 11 to 15
- 16 to 20
- 21 to 25
Deaths by Age

Number of cohort members dying

Financial year


Under 1
1 to 5
6 to 10
11 to 15
16 to 20
21 to 25
Palliative care input to the under 1 age group should be a combination of direct provision of palliative care and training and education of professionals working in perinatal, neo-natal and paediatric settings.
Recommendation 3

• Age specific palliative care services for young people (aged 16-25 years) with a life-limiting condition in Scotland should be developed.
Prevalence by Age
Although congenital anomalies had the highest prevalence in all of the younger age groups, oncology diagnoses became the most prevalent diagnosis by 21-25 years.

BUT together non-oncology diagnoses larger group
Stage of Condition by Age
Although CHAS continues to offer care to young people up to their 21st birthday, at present there is no palliative care provider specifically for young adults in Scotland. Young adults are a unique population with very different needs to children and adults and therefore they should have services designed to meet those needs.
Recommendation 4

• Palliative care services should be able to provide culturally competent care to children and young people from ALL ethnic groups.
Prevalence by Ethnicity

The graph shows the prevalence per 10,000 population for different ethnic groups over several financial years. The factors considered are:

- White
- South Asian
- Black
- Other

The prevalence increases over the years for all groups, with a particularly noticeable rise for the 'Other' group.
Recommendation 5

• Future development of palliative care services in Scotland should ensure that access to services for children and young people from areas of high deprivation is prioritised
Stage of Condition by Deprivation Category
Strengths/Limitations

Strengths
- High quality administrative data
- Refinement of ICD10 coding framework
- Transparent and repeatable methodology

Limitations
- Disclosure control limitations
- No linkage to CHAS data
- No data from other PPC providers
- ICD 10 coding ? Specificity
- Stage of condition transition definitions
The psychosocial care and support needs of families: findings and recommendations
Method

• A review of existing evidence derived from qualitative research with families
  – interviews; focus groups; questionnaires using open ended written response format
  – published in ‘peer-reviewed’ journals
  – 2009 onwards

• Two elements
  – rapid systematic review of primary research: ~300 specific conditions
  – ‘Review of reviews’: ‘high volume conditions’
Key issues / topic areas

• Two dominant themes within the evidence reviewed
  – the emotional and psychological impact of living with a life-limiting condition
  – the ‘extraordinary’ roles and responsibilities parents assume

• Further specific topic areas
  – the role of residential provision
  – experiences of exclusions & discrimination
  – parents needs as parents at end of life
“Specialist psychological and emotional care should be available to the children and young people and all family members.

• Included in this should be support for couples, and support and guidance to parents as they respond to the emotional needs of their children.

• Services caring for children and young people with life-limiting conditions should also find ways to provide opportunities for all family members to connect with and spend time with their ‘peers.’”
The supporting evidence

• The emotional worlds of children
  – sources of distress/negative emotions
  – times & situations increasing vulnerability

• The emotional worlds of parents
  – chronic emotional ‘dis-ease’ & acute distress
  – mixed feelings

• The emotional worlds of siblings
  – mixed emotional impact
  – hidden emotions
Recommendation 7

“Palliative care services should consider incorporating domestic support to families within their portfolio of services. They should also seek ways to extend provision of support to parents in order to reduce, or provide a break from, the caring demands and responsibilities placed on parents.”
The supporting evidence

- Parents’ descriptions of caring responsibilities:
  - continuous
  - pervasive

- Keeping up with domestic, maintenance and other household tasks

- Parents’ accounts of physical exhaustion
“Palliative care services in Scotland should continue to include specialist residential provision.

This provision should be extended in light of evidence of the size of the population of children with life-limiting conditions living in Scotland.”
The supporting evidence

- The particular benefits residential provision can offer:
  - opportunities for peer support
  - illness and impairment is the ‘majority experience’
  - an ‘effortless’ physical environment
  - time for parents and siblings
  - a break from caring responsibilities
  - an opportunity for sleep and physical recuperation
“Palliative care services should contribute to or support activities which seek to educate and challenge societal perceptions of impairment and disability.”
The supporting evidence

- Experiences of social exclusion, discrimination and negative attitudes reported by all family members.
  - general public
  - peers
  - extended family

- Difficult and distressing to experience and/or witness.
"Palliative care services, and other services involved in providing care at end of life, should examine current practices with respect to evidence on parents’ psychosocial needs as parents at their child’s end of life."
The supporting evidence

• Factors which influenced parents’ views about their child’s death and their subsequent acceptance/adjustment:
  – choice and control over their role in meeting child’s care needs
  – able to touch and hold their child
  – private times

• Issues of culture or ethnicity
  – the pursuit of active treatment
  – empowered to express views
  – access to interpreters
Concluding Comments

• The purpose of the ChiSP study
  – to generate a resource to support evidence-based service planning and service development

• 10 recommendations grounded in evidence:
  – the numbers and characteristics of children and young people with life-limiting conditions living in Scotland;
  – current evidence and understanding of the psychosocial needs and experiences of families
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Report now available to download:

www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf