



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Applying economic principles to children's palliative care: how can it help?

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Outline of Presentation

- Why have children's palliative care services been slow to develop?
- Using resources to greatest effect
- Are families getting what they need and what they want?
- What are current burdens on families?
- Challenges for economic research in palliative care



Why have children's palliative care services been slow to develop?

- Numbers are small
- Needs are dispersed across the country
- Needs are very individual and context matters
- Families have taken on and coped with huge challenges
- Even when available it can be difficult to broker access to services – problems can seem invisible
- Needs have grown at a time when resources are perceived to be particularly tight.



Using resources to greatest effect

- To argue for more resources we need to show current funds are being spent well – not currently the case
- Where care failure leads to unnecessary admission to hospital we achieve less for more – never justifiable
- Judging what resources are needed and who should get what is always complex – not least because individual needs and circumstances vary so much
- Given how much waste currently exists, there is clear scope to make much better use of current resources.



Are families getting what they need and what they want? 1

- How can we best find out what children and families need and want?
- Studies show that what people want depends greatly on what they know about
- How can we best elicit preferences?
- ❖ Just ask? - but how can we find the relative importance of different elements and amounts?
- ❖ Use techniques that help us to understand the relative importance of different elements?



Are families getting what they need and what they want? 2

- Needs and want – who is the best judge?
- Studies have shown that in general those helped to support their child at home are happy with the mix of support they get
- The main differences between wants and what they get cluster around priority for services that may improve skills and functioning
- There is a lot of variation in how much people want night time support (even for apparently similar needs)



Are families getting what they need and what they want? 3

- Taking a child out of the home can often increase burden (and cost) on the family
- Choice to spend a lot of disposable income indicates the priority families give to better care and their view that current provision is not adequate.



What are current burdens on families?

- In our study families chose to buy in extra care (although this was often technically impoverishing)
- Families face high costs for care of their child and for additional family needs when their sick child is at home
- Families face even higher costs when their child is in hospital
- The overall impact on household disposable incomes is around one third (almost irrespective of the level of that income)
- Failures of care often lead to avoidable hospitalisation which costs more than enhanced home care in most instances.



Challenges for economic research in palliative care

- Working out what different patterns of care cost, and who pays what
- Assessing needs and how much of need is met is complicated given variation in needs and capacities
- Measuring outcomes and effectiveness is very difficult given complexity of problems and complexity of services
- Commonly used outcome metrics do not perform well or give useful understanding
- Good support to families generally cost less and achieves more than reactive use of hospital care.





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Thank You for Your Attention