

What's in a name?

Parental constructs of palliative care

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Palliative Care

‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’



‘Is applicable early in the course of illness, **in conjunction with** other therapies that are intended to prolong life, such as chemotherapy and radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.’



American Academy of Pediatrics

Advocates an **integrated model** of palliative care ‘in which the components of palliative care are offered at diagnosis and continued throughout the course of the illness, whether the outcome ends in cure or death.’



Palliative care is...

- ✿ an **active** approach to care
- ✿ concerned more with improving quality of life than death
- ✿ compatible with efforts to modify or even cure disease



Palliative care is not...

- ✿ passive
- ✿ hand holding
- ✿ doing nothing
- ✿ giving up
- ✿ restricted to elderly patients
- ✿ restricted to patients with cancer
- ✿ euthanasia



**‘Towards an evidence-based model of
paediatric palliative care’**

Murdoch Children’s Research Institute

University of Melbourne

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Aim of the study

- ✿ To better understand the palliative care needs of children with life-limiting conditions and their families across a range of diagnoses and illness trajectories.
- ✿ Emphasis on
 - What parents understand of palliative care
 - How parents come to recognise the need for palliative care
 - How views change after experience of palliative care




Qualitative study

- ✿ In depth, semi-structured interviews with 69 bereaved parents of 45 children who had died from a range of conditions
- ✿ Selected from eligible group (age 0-18 years)
 - ✿ registered with the Victorian Paediatric Palliative Care Program, or,
 - ✿ a patient of the RCH who died of a chronic progressive condition and where there was;
 - ✿ An entry in record indicating ‘for palliative care’, or,
 - ✿ An entry indicating ‘Not for resuscitation’.

Results

- ✿ 44% of parents did not know what palliative care was
- ✿ 49% interpreted a referral as an indication that **death was imminent**
- ✿ Some parents thought of palliative care as something '**for old people with cancer**'
- ✿ Some parents thought it meant they had to **abandon hope**
- ✿ A small number equated it with **euthanasia**



Little knowledge of palliative care

- ✿ *‘At one stage we said, “What is this palliative care?” I looked it up in the dictionary.’*
- ✿ *‘...they came in on the Wednesday morning and said, “Look, we’ve organised palliative care in (town) to pop in and give you a visit when you get home” ...and they gave me her name and her number, and I will remember walking out thinking, what the hell’s palliative care?’*



Imminent Death

‘... palliative care just for me - to me just meant that it was getting close. And I guess I was a little bit scared of it.’



Confusion with Euthanasia

‘My understanding of pall - apart from the fact that he got a huge dose of the sedative to die, to help him die, I’d say no none at all.’



Palliative care as a threat to hope

'I mean some parents just want hope and if you send a palliative care team out to say that, you know...if ever we get to this stage, here's an option that's open for you, it would devastate them even more because if they have that little bit of hope, it's like you're taking away that little bit of hope.'



Holding on to hope


‘I hoped that there was going to be a miracle until I found him dead, you know. You always - you can’t help gripping onto some hope... and I remember (doctor) saying to us, you know, “Why are you so surprised? You knew things were bad,” and I said to him, “Because we had hope”.’



The risks of losing hope


'They'll then reject the child themselves and they'll move away emotionally from the issue too sometimes, but also they'll reject you because you're not supporting them anymore. They'll feel that all is lost or they'll go looking elsewhere for some crazy approach...you'll lose the whole thing.'

Paediatrician



The experience of palliative care changes these perceptions

‘Palliative care was something that cancer sufferers and old people in their last days got shipped off to an institution and slowly given pain killing drugs and die. That was my expectation of palliative care. Not a good picture, not the true picture, not at least - not what I think is a true picture now.’



‘And there was also that thing of being ready, but I think that you’d be ready earlier for palliative care services if you had a better understanding of what they were and who they were meant for.’



Implications

- ❖ Palliative care, as it is understood by most parents, is not attractive
- ❖ Misconceptions of palliative care are a barrier to receiving potentially helpful services and support
- ❖ The experience of palliative care is generally positive and many parents wish they had been referred earlier



Introducing Palliative Care

- ✿ Be aware of what preconceived ideas families may bring
- ✿ Proactively address these with them
- ✿ A ‘Hope for the best, prepare for the worst’ approach may be a way of preserving hope
- ✿ Some centres have adopted synonyms



‘Parents and health professionals find themselves forced to make an impossible choice when aspects of support, such as interventions directed to cure and those directed to comfort, are presented as a mutually exclusive dichotomy.’