



Childhood
Bereavement
Network

The research context: findings on supporting families before a death

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Childhood Bereavement Network



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- Around 280 organisations and individuals across UK
- Working to improve the range and quality of bereavement support for children and young people



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Are children whose parent is seriously ill at increased risk of difficulties?

- Comparisons between this group and national norms – mixed results
- Some studies show similar functioning
- Others studies suggest more emotional problems, esp among female adolescents and younger boys
- Methodological weaknesses



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- Thastum et al (2009) – multinational, cancer patients, 352 families. Boys aged 4-10, girls aged 11-18 had more problems than general population
- Christ et al MSK study – children reported higher levels of depression and anxiety during terminal illness than children in community sample – these levels reduced after the death (Siegal et al 1996)



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What factors are associated with greater levels of distress?

- **Poor prognosis and longer disease duration** (Welch et al 1995, Compas et al 1994)
- **Child's subjective perception of the severity of the illness** (Howes et al 1994, Compas et al 1996)
- **Gender match** (Compas et al 1994, 1996, Howes et al 1994, Visser et al 2005, Welch et al 1996)
- **Ill parent is the father** (Visser et al, 2005)
- **Distress of ill mother** (Heiney et al 1997, Howes et al 1994, Watson et al 2006)
- **Other stressors: changes in family lifestyle, ill parent's withdrawal/absence from family functions, household economic changes** (Christ 2000)

- **Multinational study of 352 children found best predictor of internalising problems was parental depression, best predictor of externalising problems was family dysfunction** (Thastum et al 2009)
- **Quality of communication and whether children have been told about illness related to children's levels of anxiety – also when illness is terminal** (Kroll et al 1998, Nelson et al 1994, Rosenheim and Reicher 1985, Watson et al 2006, Beale et al 2004, cited in Kennedy and Lloyd-Williams 2009)

- Child's perception of surviving parent's general openness highly correlated with child's level of distress (MSK - Raveis et al 1999)
- Many children not told when a parent may be facing death due to illness (Barnes et al, 2004)
- Even families with good communication before the illness can show poor communication about a parent's illness or death (Siegal et al 1996).



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What inhibits communication in the family when a parent is seriously ill?

(cited in Kennedy & Lloyd-Williams 2009)

- Parents not aware that children are experiencing distress
- Fears of breaking down in front of children
- Guilt about not being able to fulfil parenting role
- Grief over lost opportunity to see child grow up
- Not wanting to distress child
- Uncertainty

- Children say: not wanting to upset parents, not having access to professionals, age inappropriate information (Kennedy and Lloyd-Williams 2009)
- Thastum et al 2008 – Danish perspective – found children to be better informed
 - Cultural differences?
 - Age of children?
 - Stage of illness?
 - Coping styles
 - Problem focused coping – helping others, parentification
 - Emotion focused coping – distraction, keeping it in the head, wishful thinking



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What sort of communication and information do children and young people get and want?

- Age appropriate, direct information from health professionals, websites, media (Forrest et al 2006)
- Advanced cancer: children wanted honest information about parents' health and treatment; implications for future health (girls), variety of sources, access someone who understood and would keep conversation confidential (Kennedy and Lloyd-Williams, 2009)
- 'Communication rather than information may feel the crucial factor p154'



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What sort of interventions have been developed to impact on these factors?

- MSK study
 - Competence in parenting
 - Communication about the facts of the illness, treatment, death and grief reactions
 - Consistency in caregiving and planning for the family after the patient's death
- Comparative study – children reported greater reduction in anxiety and greater improvement in their perception of the surviving parent's competence and communication (Christ et al 2005)

The 'Family Talks in Cancer Care' Programme (Bugge et al, 2008)

- Norway
- 5-18 year olds, study comprised 6 families 12 children
- Coping theory of experience of belonging and competence
 - Help family talk about illness and related subjects
 - Give children knowledge and security about both the illness and the impact of the illness on daily life
 - Helping the family plan for the future
- Programme helped children feel more secure, increased knowledge and understanding, increased awareness of own role, family's strengths and who they could approach for help, helped them realize it was good and helpful to talk about the illness situation.

The Bereavement Support Service (Kennedy C et al 2008)

- Case study method – pre and post intervention evaluation design
- 6 families. Themes:
 - Thrown into chaos
 - Lost in the panic
 - Holding them steady
 - Journeying together
 - The road ahead
- Service highly valued and fully endorsed by users
- Experience and time commitment required

- Collaboration between adult oncology and child psychiatry departments of Turku University Hospital, Finland (Scmitt et al 2007)
- ‘One woman and her dog’ – Kathy Moore and Do-Good (Bereavement Care 2009)
- Collaborative inquiry ‘No, you don’t know how we feel’ – groupwork 13 participants including 9 child co-researchers from 5 families aged 7-15. (Chowns 2008, 2009)
 - Film-making
 - Egalitarian approach
 - Giving control
 - Parental death during group-work period
 - Reasons for participation

- 'This is like a club' said Rachael during the tea-break, as she munched a packet of crisps. 'We can talk about what's happening'. 'But you haven't' commented Alison, gently challenging her. 'No, but it feels like we could' was the response. (from debrief session 3)
- 'You feel so alone...no-one else knows what it's like..here you can share things...get ideas...a different perspective.' (Gemma and Natalie, in final version of film)

(from Chowns, 2008)