

Cruse Bereavement Care AGM  
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# What Helps Bereaved Children?

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# We know quite a lot about *how* children react to bereavement

- Dowdney 2000
  - In bereaved children, higher rates of:
    - Sadness
    - Specific anxieties (e.g. separation anxiety, afraid of death)
    - Behaviour Problems (e.g. tempers, concentration, sleep)
    - Guilt, despair
    - Regression (e.g. bed wetting)
  - Some actually do better at school
  - Generally boys more acting out, girls more internalising
  - Reactions generally decrease over time, but rates of problems remain higher even after a year
  - Some reactions (abdominal-pain, sibling problems, lack of interest in school) may increase over time

# Dowdney's conclusions

- *" Children do experience grief, sadness, and despair following parental death. Mild depression is frequent, and can persist for at least a year"*
- *Range of psychological symptoms, rather than a specific disorder*
- *Severe enough to warrant referral in 20% of cases*
- *Long term outcome remains difficult to clarify*
- *Closely related to parental mental health*

# What do we *know* works?

- Research evidence is poor
  - Everyone does it differently
  - Small samples
  - Lack of control groups (i.e. Any improvements might have happened anyway)
  - Lots of people drop out, or attendance is variable
- The plural of “anecdote” is not “data”

# Black & Urbanowicz (1987)

- Participants:
  - 0-16 yr olds
  - Bereaved of a parent
  - 45 families, 83 children
- Intervention:
  - 2 - 3 months after bereavement
  - 6 family therapy sessions at home at 2-3 week intervals
  - Enable communication about the death and the life of the deceased
  - Parents seen alone if necessary
  - Encourage expression of feelings

# Black & Urbanowicz (1987)

- After one year, treatment group had:
  - Fewer children whose parents were depressed
  - Fewer children who were “restless”
  - Fewer children who were biting their nails
  - Fewer parents who sought help from professional agencies
- After two years, results were not statistically significant

# Sandler et al 03

- Participants:
  - 8-16 year olds
  - Bereaved of a parent
  - 156 families, 244 children or adolescents
- Family Bereavement Programme:
  - 12 x 2hr groups for parents, children, adolescents
  - Improve relationship with carer
  - Improve mental health of carer
  - Improve self esteem and coping
  - Emotional expression

# Sandler et al 03

- 11 months after programme (but not immediately after)
- Compared to the controls (ie those that did not receive the intervention) improvements in the following areas were noted:
  - For those with highest scores initially:
    - Internalising problems reported by child
    - Internalising problems reported by carer
  - For girls not boys:
    - Internalising problems reported by child
    - Internalising problems reported by carer
    - Externalising problems reported by child
    - Externalising problems reported by carer

# Curtis & Newman 2001

- Review of research
- Only 9 met their criteria
- “Moderate empirical evidence of positive effects”
- “There is small amount of quantitative evidence that community interventions benefit parents and children within a bereaved family”
- “The case for universal inclusion of all bereaved children in community-based support programmes is as yet unproven”

# Schut & Stroebe 2005

- Children are a “special case”
- “Indications are that not all children need or benefit from intervention, and strategies of in reaching and screening for risk would seem to be advisable”
- “Newer studies support our earlier, tentative conclusion that not only secondary and tertiary but also primary prevention may be effective for children”

# What seems to be important?

- Communication about the death and the life of the deceased (usually in that order)
- Expressing emotions
- Parenting and family functioning
- Social support
- Groups

# Good-enough Parenting

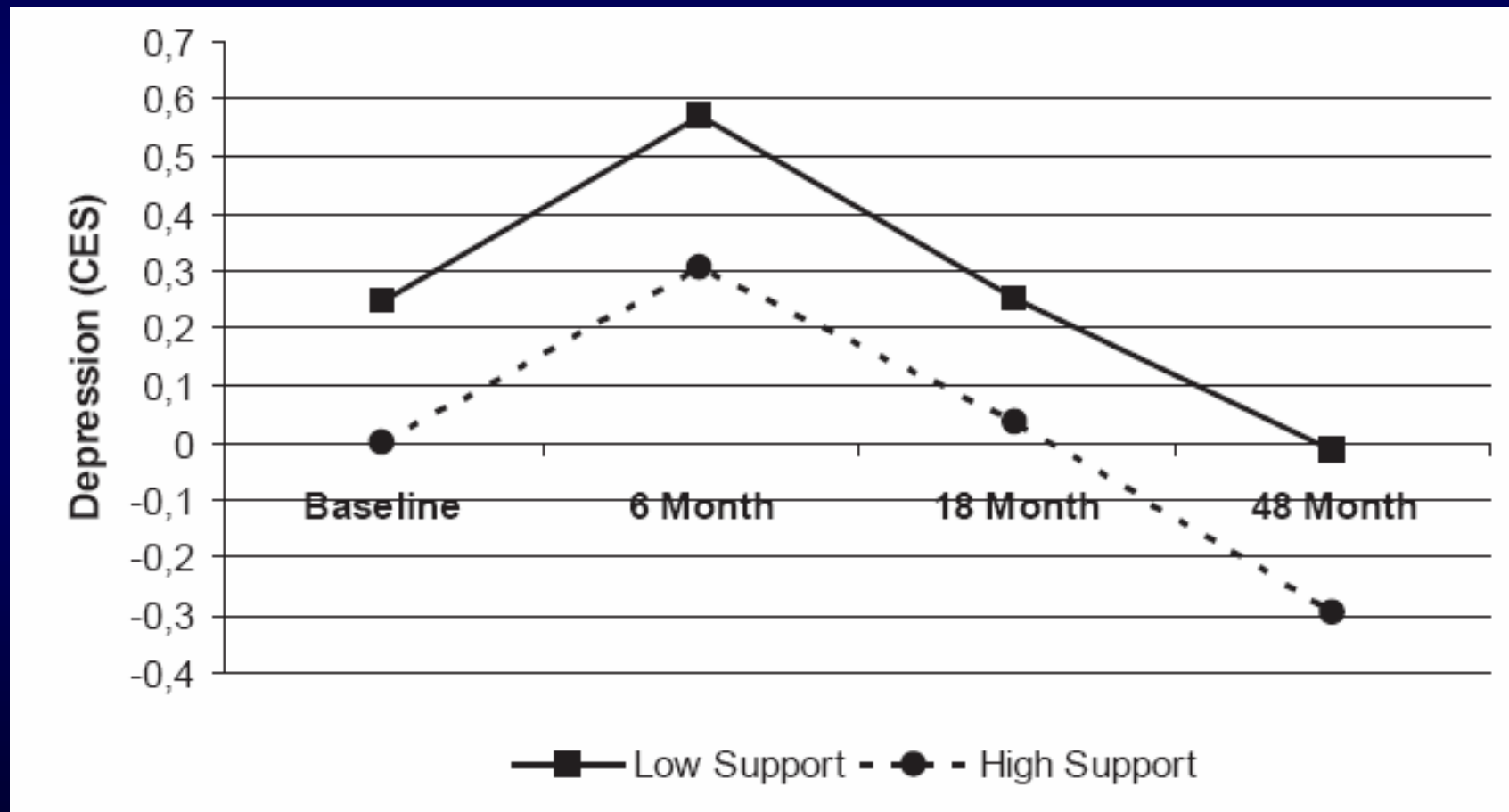
- Parenting a bereaved child, requires the same principles as parenting a non-bereaved child – just more of it
  - Bereavement might alter the child's thoughts, feelings and behaviour
  - There may be more for the parent to deal with
  - Bereavement might alter the parent's understanding of the young person, and thence their parenting of them
  - Bereavement might affect the parent too

# Love and Limits

- Quality of care and relationships is repeatedly identified as the crucial factor in helping bereaved children
  - Harrington & Harris 1999
  - Dowdney 2000
  - Dent 2005
- A good attachment is the best “antidote” to a traumatic event
- Developing a good relationship takes effort, just at a time that the parent may be pre-occupied
- Set boundaries which are clear, appropriate, and sometimes negotiable

# Stroebe et al 2005

Depressive symptoms of individuals with high or low perceived social support before, and three points after bereavement



# Learning from PTSD

- Predictors of PTSD (better predictors than the *severity* of the actual event)
  - Adult research (Brewin et al 2000):
    - Social support
    - Subsequent life stress
  - Child research (Trickey et al 2000 when we get round to it):
    - Perceived life threat
    - Social support
    - Subsequent life stress
    - Psychological functioning of parent

# Social support

- Lack of social support is associated with depression in bereaved adolescents (Balk '90)
- Bereaved adolescents tend to socially withdraw (Worden '96)

# Groups

- Sometimes, you really do have to have been there (or somewhere similar)
- Universality
- Social support more accessible
- Credibility of peers as counsellors

# What works?

- There are some things that we can be fairly sure, are useful
- The evidence base remains thin
- We can and must do better:
  - To persuade funders to fund
  - To help us to fine tune the service we offer
  - To inform the decisions made by young people and their families

- Handouts will be available from the following websites:
  - [www.traumaticstress.org.uk](http://www.traumaticstress.org.uk)
  - [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

# Step 1: Expected Changes

- If your service were effective, how would you know?
- What changes would be noticed?
- How would you know if that were true?...

## Step 2: Measures

- Age appropriate
- Valid (i.e. measure what we think they measure)
- Reliable (i.e. measure it consistently)
- Palatable
- Pragmatic

# Step 3: Implementation

- Resistance
  - More likely from the practitioners than the clients
  - Explain to the service providers:
    - Why you are going to do it
    - What you are going to do
    - How you are going to do it
    - When you are going to do it
- Data entry
- Data analysis

# E.G. WW Hypothesised Changes

- If the intervention were successful, what differences would we expect?
  - Increase in “self-esteem”
  - Improved moods and feelings (e.g. “depression” and “anxiety”)
  - Decrease in “traumatic stress”
  - Decrease in behavioural problems (e.g. aggression, concentration)

# WW Measures – before/after

- Strength & Difficulties Questionnaire (SDQ)
  - Questionnaire, 25 items rated as: “certainly true”, “somewhat true” or “not true”
  - Carer version and teacher version
  - Scores for hyperactivity, emotional problems, conduct problems, peer-problems, pro-social behaviour.
- Trauma Symptom Checklist for Children (TSCC-A)
  - Questionnaire, 44 items rated as “never”, “sometimes”, “lots of times”, “almost all the time”
  - Scores for “depression”, “anxiety”, “post-traumatic stress”, anger, dissociation
- Coopersmith Self-Esteem Inventory (SEI)
  - Questionnaire, 25 adjectives rated as “Like me” or “not like me”

# WW Difficulties

- Incomplete data
- Lack of sophistication of measures (e.g. self-esteem measure)

# WW Non-significant Results

- Some results were not significant
- This could mean that:
  - The weekend did not make a significant difference to those particular aspects of the young people's lives
  - We did not have enough young people to notice the difference
  - The questionnaires are not "sophisticated" enough

# WW Significant Results

- Self reported "anxiety" (TSSC-A)
- Self reported "depression" (TSSC-A)
- Parent reported emotional problems
- Parent reported pro-social behaviour

*The young people were less depressed, less anxious, and more sociable after the weekend than before.*

# E.G. Chums - SDQ

- Chums (Child Bereavement Service in Luton and Bedfordshire)
- Use all appropriate versions of the SDQ before and after every intervention
- They have had NO difficulties with the families
- Some families seem to think that using the SDQ makes them seem more professional

# SDQ

- 25 items questionnaire
- Each statement rated as rated as: "certainly true", "somewhat true" or "not true"
- Additional optional impact supplement or follow up
- Versions for
  - self-report (11-16)
  - Parent-report (3-16)
  - Teacher-report (3-16)
- Different scores for
  - Hyperactivity
  - emotional problems
  - conduct problems
  - peer-problems
  - pro-social behaviour.
- [www.sdqinfo.com](http://www.sdqinfo.com)

# Telling Children

- Children may actually want more information, but may be afraid to ask for fear of causing upset (Irizarry 88)
- In an understandable attempt to protect them from further distress, children are often not told the facts.
- But what if:
  - What they are told does not tally with what they saw or overheard
  - Their fantasy is worse than the reality
  - They find out the truth in an unhelpful way
  - They ask “awkward” questions
  - Different adults have different views on what should be said
  - It gets harder not easier to tell them the truth

# How to tell

- Slightly less bad coming from (or at least in the presence of) someone they know, love and trust
- With re-assurance
- Over time - a process not an event
  - Accurate
  - Repeatedly
  - Adding details (rather than taking away)
  - (Dot-to-dots, line drawing, coloured in)
- Encourage them to ask questions
  - And then you have to answer them honestly
- Using language and ideas they understand
- Euphemisms may be unhelpful
- Site visits may be really helpful

# Stroebe et al 96

- Depressive symptoms of widowed men and women with high or low perceived social support at 4-7, 14 and 24 months.

