Evaluating a bereavement programme for families who have lost a child to serious illness

Peter Hanlon[1], Eimear McMahon[2] & Suzanne Guerin[2]

1: Health Services Executive, Northern Area
2: UCD School of Psychology, University College Dublin

Camp History

- Began 1994 – Camp Jamie
- Barretstown – 1995
- Children only
- Ongoing funding issue
- Holistic care – missing piece
- Review Mission Statement
- Family attendance
- Barretstown only programme
- 3 camps

- Not a therapy camp
- Shared experience
- Time to “stop”
- Spend time as a family
- Therapeutic Recreation – challenge, success, reflection, discovery in athmosphere of fun
- Bereavement sessions, reflections, memorial service

Why research?

- Justify camp's existance
- Question efficacy
- Discover positives
- Work on negatives
- Empower self and others in the work

Research Design

- Mixed methodology used
- Quantitative Measures (Pre and Post Camp)
  - Core Bereavement Items (Burnett et. al., 1997)
  - Jimerson-Youth Common Grief Reactions Checklist (Caregiver report)
  - Bereavement Coping Self-Efficacy Scale (Benight, 2001)

Qualitative Measures

  - Open ended questions (Pre and Post Camp)
  - Semi-structured interviews exploring individuals views of the programme, its impact and what factors influence change (Follow-Up)

Participants

- 10 Families took part
  - Pre Camp Questionnaire (N= 10)
  - Post Camp Questionnaire (N= 5)
  - Post Camp Semi -Structured Interview (N= 4)
- All participants had experienced the loss of a son or daughter
- In 6 cases the death was expected
- Family Make-up
  - 3 Children (N=1)
  - 2 Children (N=5)
  - 1 Children (N=3)

Standardised Measures

- Reliabilities
  - Core Bereavement Items (α = 0.8640)
  - Bereavement Coping Self-Efficacy Scale (α = 0.9290)
  - Jimerson-Youth Common Grief Reactions Checklist (α = 0.9238)
- Means and SD at Time 1 (N = 10)

Scale	Mean (SD)	Poss. Range
CBI	32.2 (10.569)	0 - 51
BCSE	114.8 (16.422)	33 - 231
YCGR	88.166 (17.322)	65 - 260

Standardised Measures contd

- No significant change between Time 1 & Time 2
  - Core Bereavement Items (t=-.811; df=4; p>.05)
  - Bereavement Coping Self-Efficacy Scale (t= -.322 ;df=4 ; p>.05)
  - Jimerson-Youth Common Grief Reactions Checklist (t= -.806; df=3; p>.05)
- Means and SD for Time 1 and Time 2

Scale	Time 1	Time 2
CBI	32.2 (10.569)	39.89 (8.642)
BCSE	114.8 (16.422)	121.4 (8.049)
YCGR	88.166 (17.322)	91.5 (18.755)

Qualitative Pre-Camp

- Participants asked what was helping them to cope prior to coming to Barretstown
  - Most common response was '**talking**'
  - *"I love to talk about (my son), it helps me in some way"*
  - *"talking to other parents from the hospital and also to the doctors and nurses who cared for him"*
  - *"Talking to other parents who may have experienced losing a loved one"*
- Highlights different levels of **shared experience**

Qualitative Post-Camp

- One month after camp parents reported **good and bad days**
  - *"I have felt much the same, I feel good that as a family we are being proactive in our approach to bereavement, the feeling of loss does not go away"*
- Asked about impact of programme;
  - Comments on Barretstown as a **safe place** where feelings could be expressed
  - *"It gave me time to think away from home, in a safe place, where I could cry without upsetting some-one"*
  - *"I suppose it gave me the permission to smile and laugh again even through grieving… I have learnt to feel comfortable with myself and say to myself that it is ok also to feel happiness"*

Qualitative Post-Camp contd

- Impact of programme on **family**;
  - Described an **increased awareness** of family and being together
  - *"Made me realise we have to still do nice things for each often, go places, etc"*
  - *"it gave us the opportunity to be together away from the day to day routine"*
  - *"It gave us 4 days of being togather as a family… it took us away from all the everyday stresses we have to cope with along with the stress of (our daughter's) passing"*

Qualitative Post-Camp contd

- Impact of **contact with other families**
  - Typically **positive** about meeting others
  - *"I felt this was one of the most powerful things about Barretstown that there are other mums/dads/siblings who know exactly how you feel, only a person who has lost a child can have total empathy with you"*
  - *I found it very helpful and useful to hear different stories and find they had similar threads and feelings around the loss of their loved one and it didn't matter what age you suffered the loss"*
  - But also **difficult** for some …
  - *"hard that so many people after so many years in the grieving process still felt so much pain"*

Qualitative Follow-up

- Opportunity to interview some parents who were returning to camp (n = 4, 2 mothers and 2 fathers)
- Asked to reflect on **impact of programme**
  - Helped with **coping**
  - *"its helped me enormously, Its helped me with the whole bereavement process"*
  - Improved **communication** within the family
  - *"I think it has helped us to communicate… each individual in the family unit"*
  - *I think it helped us enormously as a family lets say, it was the first and only time the we really got together to talk about it"*

Qualitative Follow-up contd

- Asked to identify significant aspects of programme
  - **Shared experience**
  - *"the one thing I find is that we're all in the same boat, we generally have the same experiences, some of them are more prolonged or deeper than other, but in essence the experience that I have is the same as the other family has … as a result of that you can safely say then you know, I'm not alone I'm not the only one"*
  - **Time as a family**
  - *"as a family we were able to get together and it was absolutely invaluable"*
  - Importance of **multiple visits** and **fun** activities

Research Conclusions

- No significant changes on quantitative measures
- Key themes emerged from qualitative data
  - Families positive about impact but still grieving
  - Shared experience with other families is central to the impact
  - Attending as a family also important
- Consistency in the themes emerging from surveys post camp and from interviews at follow-up
- Need to consider representativeness of sample – all families have sought support
- Small sample but insights given are invaluable

Implications

- Currently reviewing data collected for specific recommendations from families but suggestions include more one-to-one sessions and more visits
- Possible pre and post camp interventions
- Examine camp schedule and possible adjustment
- Explore number of camp attendances
- Development of Leader in Training Programme
- Incorporating bereavement team into main programme team
- Discuss with team as all above have financial implications