Exploring the role of therapeutic recreation in supporting families who have lost a child to serious illness

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(Brief) 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
- Three camp cycle
- Addition of “Reunion Camp” Oct 2011
Key Elements

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

- Tradition of research at Barretstown
- Justify camp’s existence
- Explore the nature of the programme
- Question efficacy
- Discover positives
- Work on negatives
- Empower self and others in the work
Research Aims

• To describe the historical development of a bereavement programme within the context of a therapeutic recreation programme for families affected by serious childhood illness.

• To assess and describe the model of the programme.

• To explore the potential contribution of the programme if any.

• To inform the further development of the bereavement programme.
Five Phases

• Phase 1 – Initial exploratory mixed-methods pilot study.
• Phase 2 – A retrospective study (documentary analysis and staff interviews) to chart the development of a bereavement programme over time.
• Phase 3 – A practitioner-based study drawing on field notes to chart the nature of the bereavement sessions.
• Phase 4 – An interview study with parents attending reunion camp who attended camp 5 – 7 years ago.
• Phase 5 – Mixed-methods case studies with parents attending the three-camp cycle over the course of a 12-month period.
Phase 1: Pilot Study

- 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 six cases the death was expected

- Family make-up
  - 3 Children (n=1)
  - 2 Children (n=5)
  - 1 Children (n=3)
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 other, 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 together 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
Phase 1: Conclusions

- 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.
- Informed later phases of the study.
Phase 5: Case Studies

- Parents from two cycles (Autumn 2009, Spring 2010) invited to take part.
- Quantitative questionnaires will be completed before first attendance and after each of the 3 camps:
  - Social Support Measure (MSPSS)
  - Family Assessment Device
  - Bereavement Coping Self-efficacy Scale
  - Problems and Goals Form
  - Open-ended survey
- Qualitative interviews: Parents completed a brief interview (either in person or by telephone) after their attendance at the final camp
Parents’ Views: Initial Patterns

• “I thought it was excellent, I thought it was nice to see that there were all other people who were in the same situation as us. And from camp 1 when you go in you can see everyone’s face and you can show your real face, when your in the real world your pretending or whatever to get along but I guess when your with the people in that you can see their face if you like, their pain. To see that there were other people in the world, who have suffered what we went through”. Dad
Parents’ Views: Initial Patterns

• “There togetherness with the people at the camp and I thought it was excellent that we went back and met the same people because you could see the progression in the people”. Mam
Parents’ Views: Initial Patterns

• “It was fantastic just to get to go someplace as beautiful and wonderful as BGC because I love nature and all of that so that’s really a fantastic place to go and you just really get back to basics, and it’s just the time out, time it gives you just to relax and to just be comfortable with other people who knew where you were at or just to feel comfortable with people because you just don’t feel comfortable with so many people when something like this happens” Dad
Parents’ Views: Initial Patterns

• “I think also for the kids it was helpful to see other kids there that there brothers and sisters can die as well and that they weren’t any way alien, that was a really big thing” Dad
Parents’ Views: Initial Patterns

• "…my abiding memory of the first one (camp) I don’t think I was ever looked after so well”

• “it really did bring a lot of things to the fore and helped to relax and maybe talk a little about things” Mam

• “before we went to camp I think we were feeling that …there was a lot of time we were separated in our own thoughts and I suppose very distant, close in physical but distant mentally” Dad
Parents’ Views: Initial Patterns

• “am I indulging too much, am I spending too much time thinking about .. (dead Daughter) and ignoring other things so I think that gave me more permission” Mam

• “I enjoyed all the camps, lovely, relaxed. Time to sit back, chill, pause… I suppose I would work six days a week all the time….to actually have a break” Dad
Next Steps

• Need to complete data collection and analysis.
• Key issue is the integration of findings from across the different phases.
• Important to identify the key findings relevant to exploring the potential contribution of this model of service.
• Dissemination of findings though presentations and publications will be important.