Exploring the Potential Contribution of a Therapeutic Recreation-Based Bereavement Programme for Families who have Lost a Child to Serious Illness

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Perspectives on Family Grief

• De Spelder & Strickland (2005 p. 238) “our conventional views of bereavement, grief and mourning are being revised.”

• Gilbert (1996): as well as being an experience for each family member, a child’s death impacts on the family as a unit

Available Interventions

- Group-based Support
- Peer Support
- One to One Support
Barretstown Bereavement Programme

• Barretstown in Co. Kildare, Ireland
• Member of Serious Fun Children’s Network
• Bereavement programme has evolved over time
  – 3 camp cycle over one year
  – 3 night residential camp
  – Reunion camp (new development)
  – Includes parent volunteers with experience of bereavement
Models Used in the Programme

BEREAVEMENT: Continuing Bonds

BEREAVEMENT: Narrative Approach

THERAPEUTIC RECREATION: Health Promotion/Health Protection Model
Therapeutic Recreation (TR)

- Purpose of TR "the provision of treatment services and the provision of recreation services to persons with illnesses or disabling conditions" and to "restore, remediate or rehabilitate" those who participate (Association of Therapeutic Recreation of America, 1997, Definition statement, para. 1).

[Image: Fun model]

Barretstown TR model as reported by Kiernan et al. (2004).
Elements of TR (Jennings & Guerin, 2014)

Learned Helplessness
- Loss of Control

Concepts
- Choice/Freedom
- Flow
- Perceived Constraint
- Locus of Control
- Personal Causation
- Intrinsic Motivation

Operations
- Degree of Control
- Challenge
- Development of Skills/Knowledge/Attitudes
- Developing Competence/Mastery

Effects
- Empowerment
- Accomplishment
- Enjoyment
- Self-efficacy
- Self-determination

Outcomes
- Leisure Lifestyle
- High Level Wellness
- Sense of Well-Being

Visual Representation of Key Elements of TR Models (Jennings & Guerin 2014)
Bereavement Components on Camp

• Approximately 5 – 6 hours each weekend
• Movies that address issues of loss
  – Camp 1 – The Lion King
  – Camp 2 – My Girl
  – Camp 3 – The Bridge to Terabithia
• Reflections – Focus on remembering family members
  – Music
  – Spoken word
  – Photographs
  – Candles
• Bereavement group sessions
Celebration of Life

- More elaborate setting
- Candle heart
- Photographs (individual, family)
- Flowers
- Gift (3rd camp)
- Focus on remembering & celebrating
The Present Study

• Objectives:
  – describe the nature of a bereavement programme delivered within the context of a therapeutic recreation programme, for families who have lost a child to serious childhood illness;
  – **to explore staff and parent perspectives on the potential contribution of the TR-based bereavement programme on families who participate.**
Methodology

• Informed by Medical Research Council Framework (Campbell et al, 2000)
• Mixed methods action research study
• Key components
  – Documentary analysis & researcher reflections
  – Mixed methods longitudinal study of parents taking part in a 3-camp cycle
    • Surveys (9 families, n = 13) & case studies (3 families, n = 6)
  – Qualitative study of parents taking part in reunion camp (n = 6)
  – Qualitative study of staff perspectives (n = 6)
Integrated Findings from Parents

The Grief Journey... Confronts Grief Physical & Emotional Symptoms Looking for Support Evidence of Coping Understanding Coping Continuing On

Between Families – Fellowship, Normalisation

Within Families – Communication, Fun, Time

Connection to the Child Who Died

Safety – Needs Met, etc.

Within Camp – Reflection, Activities, Fun, Challenge
The Grief Journey

- **Feelings** vary - from “doing well and coping” to *the depths of depression every time I think of her*.

- **Confronted** by how the loss has impacted upon them **physically or emotionally**.

- Parents **search** for supportive intervention but are hesitant. Feared camp might “*make us worse*”.

- **Coping**: Families report they are “*doing well*” and “*initial difficulties and grief, the highs and low seem to have smoothened or lessened*”.

- Desire to **continue on** with the business of living, but maintain the connection to their child - “*she is with us*”.
Contribution of the Programme

Within Families

- **Communication**: “we speak about him regularly and can now enjoy and laugh at some of the memories”.

- **Relationship** concerns “I have no enthusiasm to join in with/feel isolated from my partner”.

- Opportunity to **have fun** - “you realised that you were having a bit of fun”.

Between Families

- Desire “to meet others who have experienced similar losses and find folk to talk with”

- **Fellowship** of parents - “wonderful sense of being special among other special families”

- **Normalising** their experience
Contribution of the Programme (Contd)

**Within Camp**
- Offers **time away** from outside world
- **Fun activities** as a counterbalance
- **Bereavement sessions** “beautifully difficult”.
- **Challenge** but “completely invaluable experience, teaching us so much about ourselves”

**Safety**
- Camp was “safe at every level”.
- Allowing children to do more “adventurous things”.
- Among other parents who “get it”.
- Camp can “wrap me up and mind me, keep me safe until Sunday”.
Connections

- **Ongoing connection to the child who died:**
  - Connection to the child is ever present “felt close to him before Barretstown and this has not changed to any greater or lesser extent”.
  - Connection as courage - *if I hadn’t had gone through what I had [child’s death] I wouldn’t have done [the high ropes course]”*
  - Comments on reflections and celebrations of life - allowed parents to “*hear their names said out loud, only usually heard at anniversary mass*”
  - “*Barretstown is a place where you meet people and can talk openly about your child*”. 
Potential Impact

- Perceptions of positive impact on coping with bereavement, access to support and implications for family functioning.
- Staff stressed the opportunity to be yourself and not feel judged.
- Meeting others, not feeling judged, having fun, while still remembering the child who died appears to be important elements of this contribution.
- Bereavement components made parents aware of their own and other family members’ grief.
- Parents would recommend the programme to other bereaved parents.
What does it do?

- Fellowship and shared experience addresses isolation and offers a non-judgmental place to share stories, discuss difficulties, come together as a family, and create a support network.
- Children can be remembered and celebrated, but surviving family members can also reinvest in themselves and each other, and have fun again.
- The safety of the environment allows families to reconnect with their child and siblings.
- Residential nature creates a safe space.
Reflections on the Study

• Action research design conducted in one setting = may reflect a possibly unique context.

• Study included multiple stakeholders’ views and multiple methods of data collection. A dynamic set of data was collected.
  – BUT not views directly from children!

• Longitudinal element allow for examination of patterns over time

• Rigorous approach to the analysis of data

• Need for further research to systematically test the model for impact on families
Potential Contribution of the Model

• Findings suggest the programme, which combines TR with a bereavement component, may be a valuable one in the support of families who have had a child die from serious illness.

• Potential for this model to be applied in other TR camps (Serious Fun Network)

• Closing the holistic loop - ensuring the availability of support through all areas and periods of a children’s illness and subsequent death
Thanks for your attention

Any questions?

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