Therapeutic Recreation as a Support for Bereaved Families

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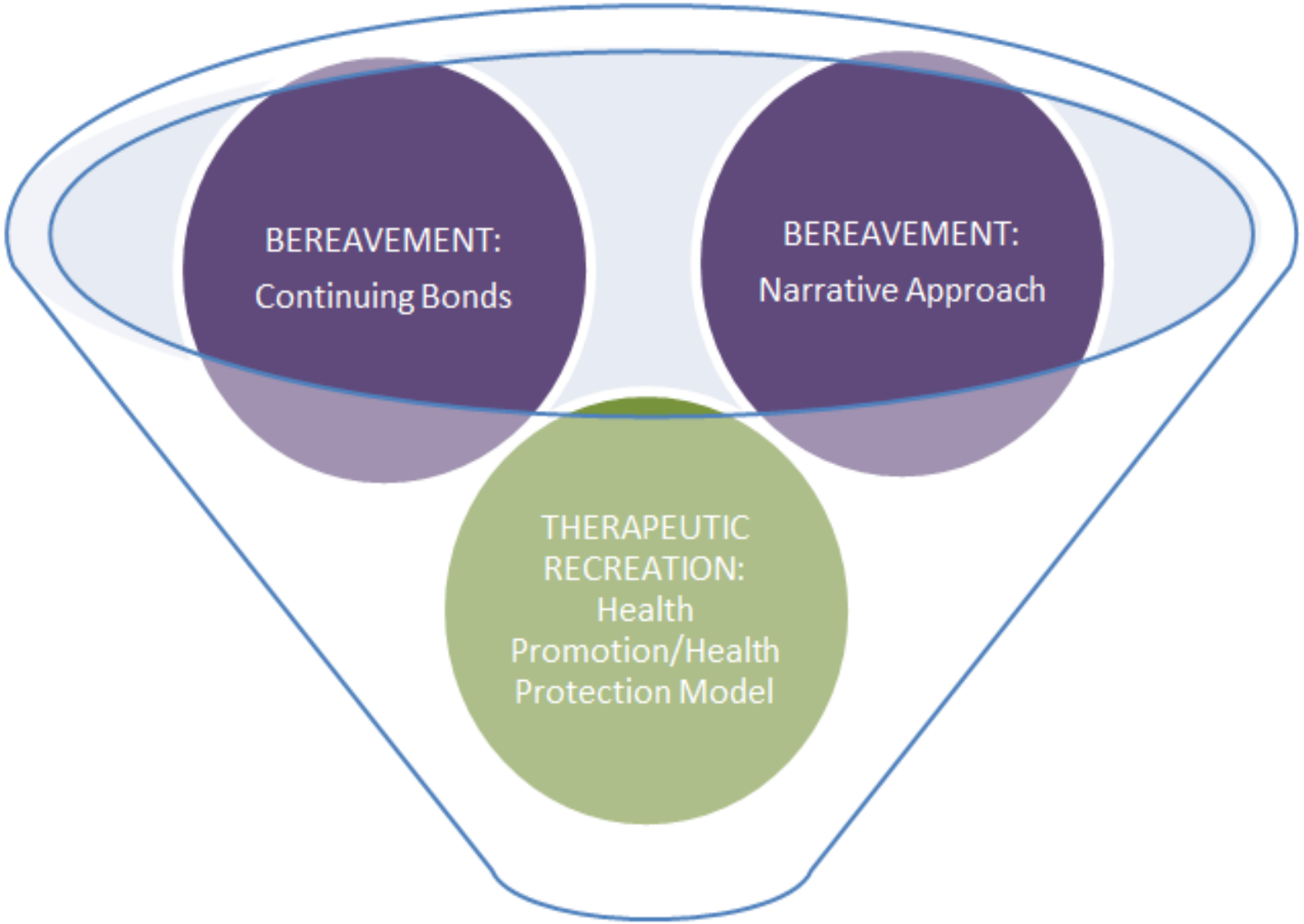
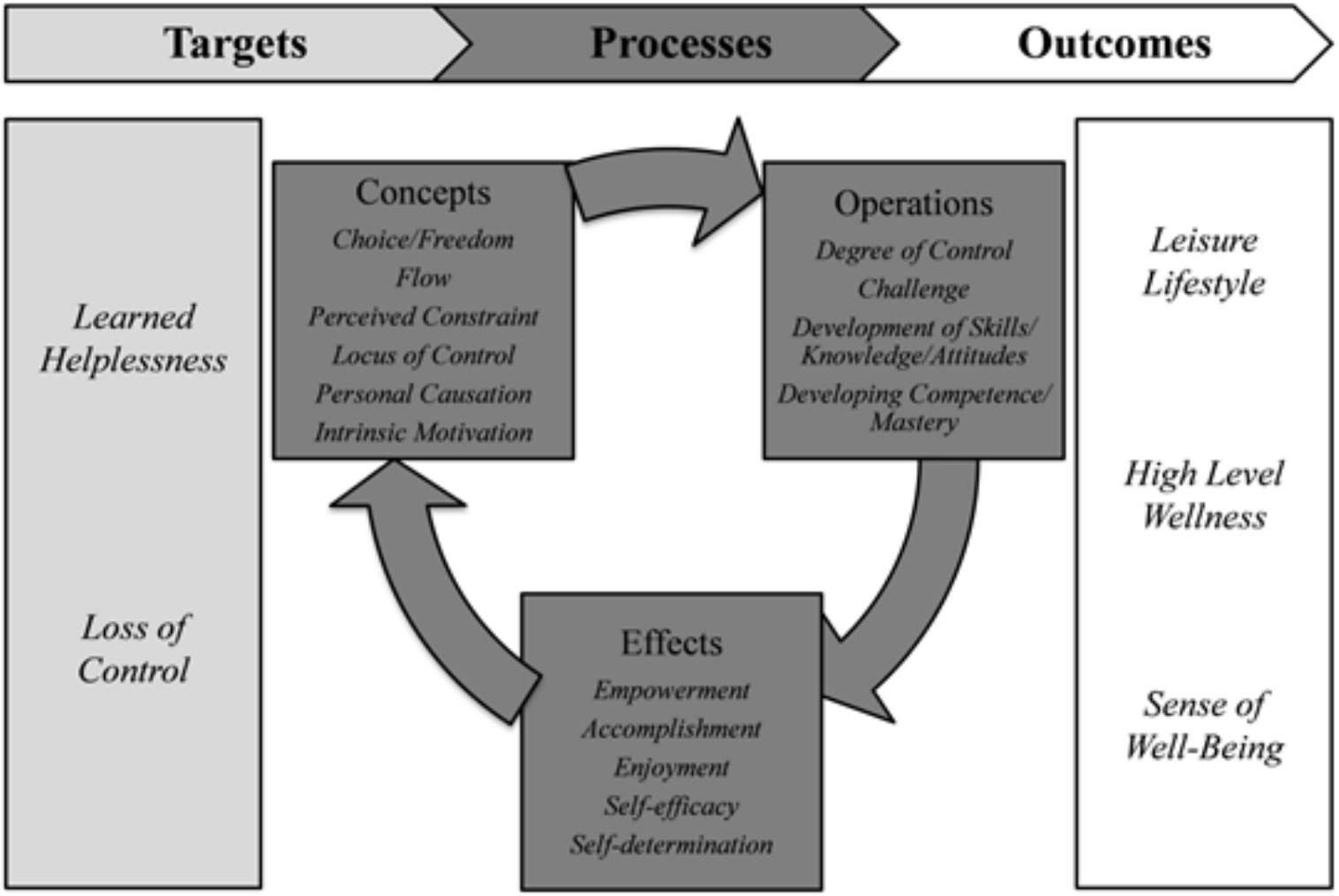
Key Elements of the Model



Therapeutic Recreation (TR)

Developed in the US and strongly associated with the camping movement, the primary purpose of TR (as identified by the Association of Therapeutic Recreation of America, 1997) is *"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 in it (Definition statement, para. 1).

Elements of TR



Visual Representation of Key elements of TR Models (Jennings & Guerin 2014)

Overall 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.

Research Structure: 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 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

Case Study Participants

Family	Child	Age	Cause	T/since
1 (M&D)	S	2yrs	Cancer	15 mths
2 (M&D)	D	2yrs	Leuk	21 mths
3 (M&D)	D	18yrs	Vasc*	10 mths

Before Camp and Expectations

- Negative wellbeing – *“stressed, depressed, lacking confidence”*
- Concerned about grief – *“ am I indulging too much. Am I spending too much time thinking of [child] and ignoring other things”*
- Life after grief – *“ the birth of our last child was emotionally mixed but has greatly added to our family”*
- Specific concerns for Dads – *“he did not have the same opportunities to talk to others”*
- Evidence of coping – *“I have seen worse things than you have, you cant beat me”*

Expectations of and for Camp

- Children as key motivation – *“my children need me to be there [Camp]*
- Seen as a positive for Fathers – *“ just to be able to talk to people…I was very keen for [Father] to go”*
- Desire to meet others – *“in the same situation as us”*
- Concerned about negative impact – *“make us worse than we were… a real downer”*
- *Looking for coping strategies – “ we have worked hard in the times since [child] died to find good ways of coping”*
- *Moving past grief – “work our way through this”*

At, After, Between Camps – Camp 1

- Physical effects of camp – *" I think the first camp is shattering"*
- Sense positive change – *"wonderful and feeling uplifted"*
- Emotional effects of camp – *" it was very, very emotional that first week end"*
- Experiences of activities
  - TR – "*the best way to get people to really talk about things that are important is to get them to do something else"*
  - *Ber Comp – "I thought the last evening at camp, the night thing (Celebration of Life) was superb"*

Camp 1 continued

- Talk about child who died / compare stories – *"it was interesting to see, to hear other peoples stories, it kind of made you feel almost grateful for the way our child died"*
- *Evidence of coping – "over all very well came from camp quite refreshed and happy"*
- Feeling (sense) of safety – *" I think first and foremost it's a safe place on every level"*

At, After, Between Camps – Camp 2

- Positive change – “ busy but handling activity well”
- Manifestations of loss – “ the dreadful pain of the early months”
- Managing grief – “I read books on the subject of grief, I went to meetings”
- *Relaxation – “for myself it relaxed me”*
- Connection to the child who died – *“a lot of time [child] is with me nd must be helping me. Loving her is easy but she is not here to share the laughter and the trials, so it has changed”*

Camp 2 continued

- Mixed views of coping
  - + “managing to rebuild our lives”
  - - *“ Not too bad when I am among people but still have difficulty being in the house alone and sleep with the light on”*
- *Having fun – “I think it was the first time feeling that I was actually having fun”*

At, After, Between Camps – Camp 3

- Finishing the programme
  - + *“seeing other people survive”*
  - - *“everyone is not whole again”*

- *Connection to child who died*
  - + *“it gives you that space to be there and you don’t have anything else to think of and that warmth of being with the person”*
  - - *“ finding it harder to replay some of the memories in my head”*

Self-Reported Impact of Attendance

- Feeling of safety – *"a safe place that gave us permission"*
- Sense of belonging - *" a wonderful sense of being special among other special families" " very liberating"*
- Opportunity to share stories - *" opportunity to talk about [child] or listen to others tell their stories"*
- Break as a family *" getting away as a family"*
- See Dad relax and be comfortable *" to see him chill out and relax with other families…he had worked non stop since [child] died"*

Self-reported Impact continued

- Benefits for sibs/ understanding sib grief
  - “seeing him have a good time was important” “gave insights in to sibling grief”
- Enjoyment and fun *“ showing us that we could do enjoyable things as a family and a couple again”*
- Physical and emotional impact *“ emotionally exhausting and draining “*
- Connection child who died *“ Highlighted (for siblings) the bond they had with [child]*
- *Not being judged “ not having to worry about what others were thinking about what we said”*

Parents' Views of Programme

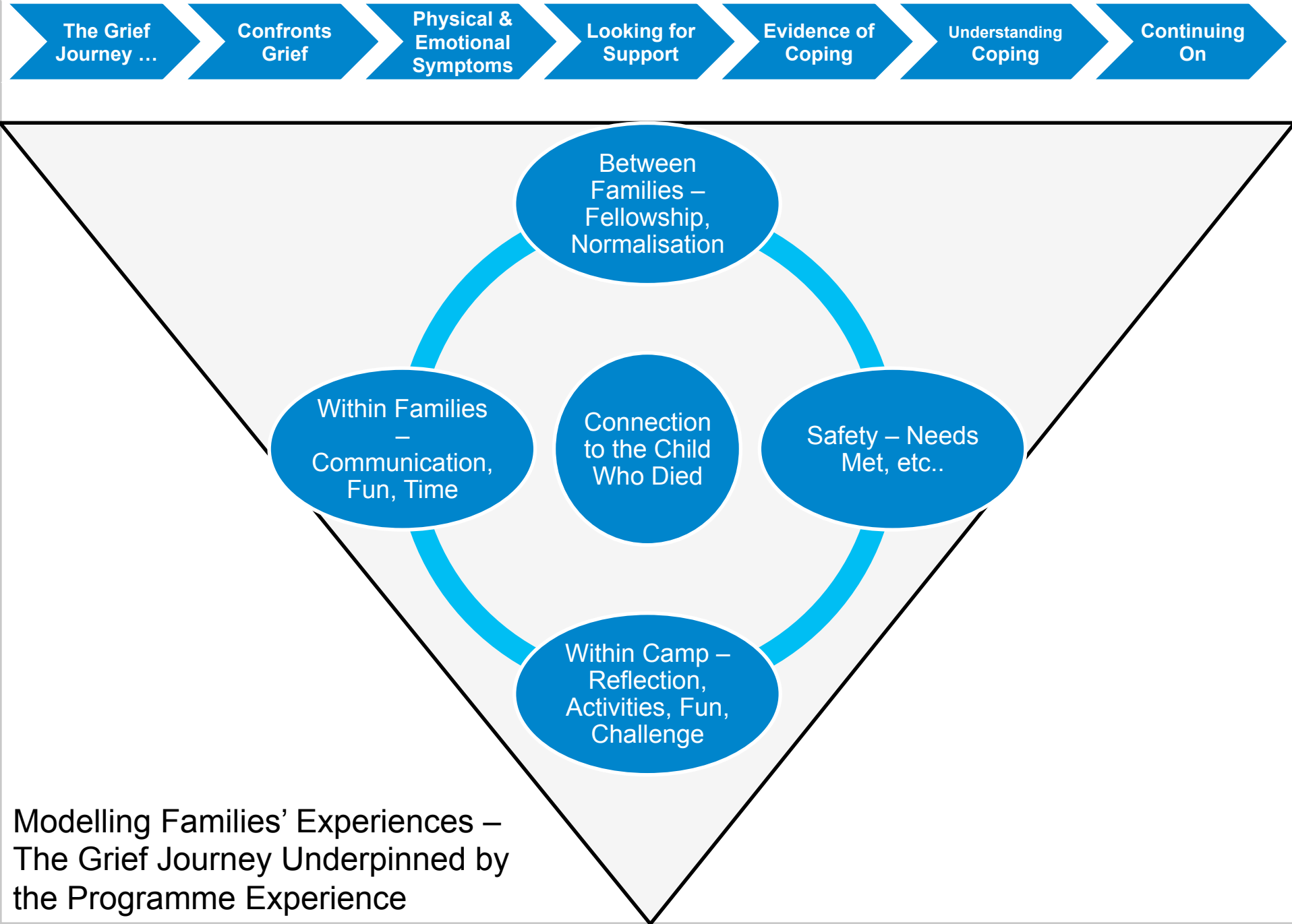
- Activities and TR - *"breaks down barriers", "high ropes"*
- Importance of activities and TR - *" evening programme was a good thing after reflections as it helped to relax things"*
- Bereavement Component:
  - Reflection/Celebration as:
    - +*"a rare moment of focus and symbolism"*
    - - *"the pain is palpable in the room on the first week end"*
- Bereavement - *"difficult but beautifully difficult"*

Parents' Views continued

- Key features of camp – The Barretstown effect
  - Opportunity to meet other families - *"knowing there are others out there dealing with their own but similar pain*"
  - Not feel judged - *"measure the progress and recovery of the family in a completely safe and non judgemental environment"*
  - *Fun* - " enjoying ourselves without reservation"
  - Focus on child who died - *"provided a time and space where we were able to focus on our daughter completely"*
  - Seen as a positive for Dads *"zip off that suit"*

Parents' Views - Negative

- Outside intrusions – " a work intrusion that destroyed the value of my first day"
- Reality of loss "it changes but it never gets easier to accept"
- Dominant parents "I felt she dominated the session"
- Participation – *" we were told before we went down that you didn't have to do anything you didn't want to do. And here was this [named volunteer] chasing us around all the time"*



Modelling Families' Experiences – The Grief Journey Underpinned by the Programme Experience

The Model

- “… fellowship and shared experience addresses isolation and offers a non-judgmental place to share stories, discuss difficulties (separately and together), come together as a family, and create a support network, as both parents and staff reported in the findings … 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 this environment allows families … an opportunity to reconnect with their child and siblings in a way that they may have been unable to do up to then … the residential nature of the programme and the operation of the programme appear to create a safe space in which this can happen. A specific aspect of the model and how it engages with parents and children appears to have the potential to offer fathers unique engagement”

Reflections

- Strengths;
  - Study explicitly focuses on loss following serious illness – examines this unique group
  - Mixed methods allows multiple perspectives
  - Contemporaneous engagement with families and longitudinal involvement
- Limitations;
  - Small sample size,
  - Certain illness groups reflecting programme focus
  - Parents' views only

Implications for Research

- Very little published research in this area but more in recent times
- Predominantly surviving child grief camp focus
- Some shift towards family-focused camps in the literature but little explicit detail regarding the specific content of the programmes
- Little explicit naming of therapeutic recreation as the programme model for camping programmes

- This study is one of the first to systematically explore a TR-based, family bereavement programme where children have died from serious illness.