Parents’ experiences of a therapeutic programme for families effected by childhood cancer

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Background: Therapeutic recreation

• ‘the process of helping people affected by illness, disability and/or other disabling conditions to develop and use their leisure in ways that enhance their health, independence and well-being’

(National Therapeutic Recreation Society, 1996)
Barretstown

- Founded in 1994, situated around Barretstown Castle, Co Kildare, Ireland.
- Information available at www.barretstown.org
- Member of US Hole in the Wall Gang Association
- Aim: to enhance the psychosocial functioning of children and families affected by childhood illness
- Family Programme: 3-4 day sessions
- Activities form basis of programme;
  - Arts & crafts, Creative writing, Drama, Photography
  - Low & high ropes, Horse-riding, Canoeing, Camping
  - Crazy & Lazy, Early birds, Evening activities
- Based on a model of Therapeutic Recreation
Barretstown model

- (Kiernan et al., 2002)
Aims of present study

• To examine the psychosocial impact on families of attending Barretstown’s family programme
• To evaluate the family programme from the families’ perspectives and develop the programme accordingly
Design of the present study

• Design: Mixed methods design incorporating:
  – Complex 2x3 design (2 groups tested over 3 time points)
  – Standardised measures & qualitative data

• Participants: Irish families who have had at least one child diagnosed with a serious illness
  – Group 1 (Barretstown families): families who have attended Barretstown’s family programme
  – Group 2 (Comparison families): families who have not attended Barretstown’s family programme

• Timeframe:
  – Time 1 (baseline), Time 2 (one month later), Time 3 (four months later)
Measures & materials

- **Standardised measures:**
  - Impact of Chronic Illness on Family Scale (Stein & Reissmann, 1980)
  - Multidimensional Scale of Perceived Social Support / MSPSS (Zimet et al., 1988)

- **Qualitative data** (Barretstown families only)
  - Semi-structured interviews exploring parents’ experiences of illness and of Barretstown’s programme
  - Children’s comments and drawings
# Participation rates

## Original sample participation & attrition

<table>
<thead>
<tr>
<th></th>
<th>Invited</th>
<th>Consented</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barretstown</strong></td>
<td>95</td>
<td>51</td>
<td>35</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(54%)*</td>
<td>(69%)**</td>
<td>(49%)**</td>
<td>(37%)**</td>
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<tr>
<td><strong>Comparison</strong></td>
<td>133</td>
<td>60</td>
<td>51</td>
<td>37</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(45%)*</td>
<td>(85%)**</td>
<td>(55%)**</td>
<td>(47%)**</td>
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<tr>
<td><strong>Total</strong></td>
<td>228</td>
<td>111</td>
<td>86</td>
<td>61</td>
<td>46</td>
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<tr>
<td></td>
<td></td>
<td>(49%)*</td>
<td>(77%)**</td>
<td>(55%)**</td>
<td>(41%)**</td>
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</tbody>
</table>

* = participation rate, i.e. % of those invited who consented  
** = retention rate, i.e. % of those who consented who were retained @ Times 1, 2 & 3.
Comparability of groups (T1)

- No significant differences between groups for
  - Age of child with diagnosis
  - Age of parents
  - Number of siblings
  - Time since diagnosis
  - Time since treatment
  - Scores on standardised measures at Time 1

- Significant difference in diagnosis b/w groups due to lack of access to ALL (Acute Lymphoblastic Leukaemia) families
Interview analysis

- 13 families (out of 24) took part in an interview at Time 2 (one month after participation)
- 9 families took part in a further interview at Time 3 (four months after participation)
- Interviews analysed using thematic content analysis (Guerin & Hennessy, 2002; Braun & Clarke, 2006)
- Inter-rater reliability assessed to ensure the credibility of the analysis
Preliminary findings: Evaluation (T2)

- **Activities:** ‘I got to do things I have never done before’

- **Staff:** ‘They (the staff) really get down to the kids’ level and they love that’

- **General atmosphere:** ‘It’s everywhere, it’s in the atmosphere, this happy glowing feeling, loving family feeling’

- **Programme structure:** ‘I’m going to sound like a terrible mother here but it (best thing) was the fact that I got to leave my kids!’

Level of organisation
Preliminary findings: Evaluation (T2)

Meeting other families

• Sharing experiences
• Mutual understanding
• Reduced isolation: ‘It's just that you’re not alone...there are other families out there that go through similar things’

Recommendations for programme development

• Structural aspects EG length of programme, nature of activities, structure of activity groups

‘Would have loved another day cos you arrive there on Friday and you’re going home Sunday morning’
Preliminary findings: General impact (T2)

• **Difficult to describe impact:** ‘You couldn’t put a value on what it does for you’

• **Fun / enjoyment / Memories:** ‘All we talked about was Barretstown for weeks and weeks you know, we just loved it so much’

• **Respite:** ‘Having the freedom you know, from the routine of going to the hospital, being in the hospital, giving medicine, all of that’

• **Building of confidence / esteem:** ‘It (Barretstown) has given us a certain empowerment, ye know if you want to do something do it’
Preliminary findings: Impact on family (T2)

- **Family relationships:** ‘Why can’t every family go to places like Barretstown ... I think it’s probably really good for relationships within the family’

- **Increased awareness:** ‘I think it taught us that we were being a bit over protective with the family as parents’

- **Perspective:** ‘If we learned anything it was that the kids have fun together and laugh and even though you were living with a very very serious illness that you can still be a normal family and laugh and have fun together and it’s good to do this, not to let the illness take over your life’

- **Increased participation:** ‘And because when he was in Barretstown he loved the shows and the music so much when we came back I sent him to (music class)’
Preliminary findings: Mediating factors (T2)

- **Exceeding expectations** (EG in relation to participation in activities)
- **Interaction with other families:** ‘It’s (the programme) a collective group experience you know’
- **Atmosphere /safety:** ‘The kids were all well looked after you could relax, which is something you never funnly do, well I don’t’
- **Treatment /illness status:** ‘Before Barretstown we probably wouldn’t have been so relaxed about leavin him with other people, although maybe it might be more because the (Hickman) line is out that I’m more relaxed about leaving him and letting him go to playschool and different things’
IT REALLY IS...

FORT OF FUN

Thanks for a brilliant time...
Conclusions & implications

- Value of exploring families qualitative insights
- Parents clearly see significant benefit from participating in the programme
- Preliminary findings encouraging, need to explore views at Time 3 to consider maintenance of any positive impact
- Therapeutic Recreation as a potential psychosocial intervention
Thank you for your attention

• We would like to thank Cancer Research Ireland for supporting this study.

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