Examining the role of a therapeutic recreation programme in mitigating the impact of childhood cancer

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Presentation outline

- Impact of childhood cancer
- The Barretstown programme
- Design of study & preliminary findings
- Plan for ongoing study

Impact of childhood cancer

- Increase in research looking at psychosocial impact of serious childhood illness on children and families
- Overall – greater risk of maladjustment *("all else being equal", Cohen, 1999)*
- Considerable individual variation *("all else is not equal", Cohen, 1999)*
- Family functioning significant predictor of adjustment
- Shift in focus: *'sick child'* to *'sick child within the family' (Zimmermann Tansella, 1995)*
- Implications for objectives of psychosocial interventions

Mitigating Impact of childhood cancer

- Increase in research looking at psychosocial impact of serious childhood illness on children and families
- Overall – greater risk of maladjustment *("all else being equal", Cohen, 1999)*
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- Implications for objectives of psychosocial interventions

Barretstown

- Founded in 1994, member of American Hole in the Wall Gang Camps Association
- Aim: to enhance the psychosocial functioning of children & families affected by serious childhood illness
- Programme grounded in a model of therapeutic recreation: (the use of recreational or leisure activities as a form of psychosocial intervention; Austin, 1998)
- Model: FUN – CHALLENGE – SUCCESS – REFLECTION (Kiernan et al., 2001)
- Family programme (1997): 3-4 day camps run in spring and autumn months

Aims of the present study

1. To examine the impact on families of attending Barretstown's family programme

2. To evaluate the family programme from the family's perspective and develop the programme accordingly

3. To provide insight into the impact of serious childhood illness on Irish families

Outline of present study (1)

- Design: 2x3 design (two groups tested over three time points)
- 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 (n = 50)
- Group 2 (Comparison families): families who have not attended Barretstown's family programme (n = 50)
- Time 1 (baseline), Time 2 (one month), Time 3 (four months)

Outline of present study (2)

- Questionnaire measures (Time 1, 2 &3):
  - Impact of Chronic Illness on Family Scale (Stein & Reissmann, 1980)
  - Family Illness Beliefs Inventory/FIBI (Kazak et al., 2004)
  - Multidimensional Scale of Perceived Social Support (Zimet et al., 1988)
  - General Demographic Questionnaire (modified at each time point)

- Interviews (Barretstown families only)
  - Time 2: semi-structured interview exploring families experiences of illness and of Barretstown's family programme
  - Time 3: semi structured interview exploring any continuing impact on families of attending Barretstown's family programme

Data collection to date

Barretstown families

Questionnaire Data:

Time 1: 11 families (44% response rate)

Time 2: 9 families (81% response rate)

Time 3: 7 families to date (ongoing)

Interviews:

Time 2: 7 families

Time 3: 5 families (ongoing)

Preliminary Findings: Quantitative Data

- Reliabilities of standardised measures:

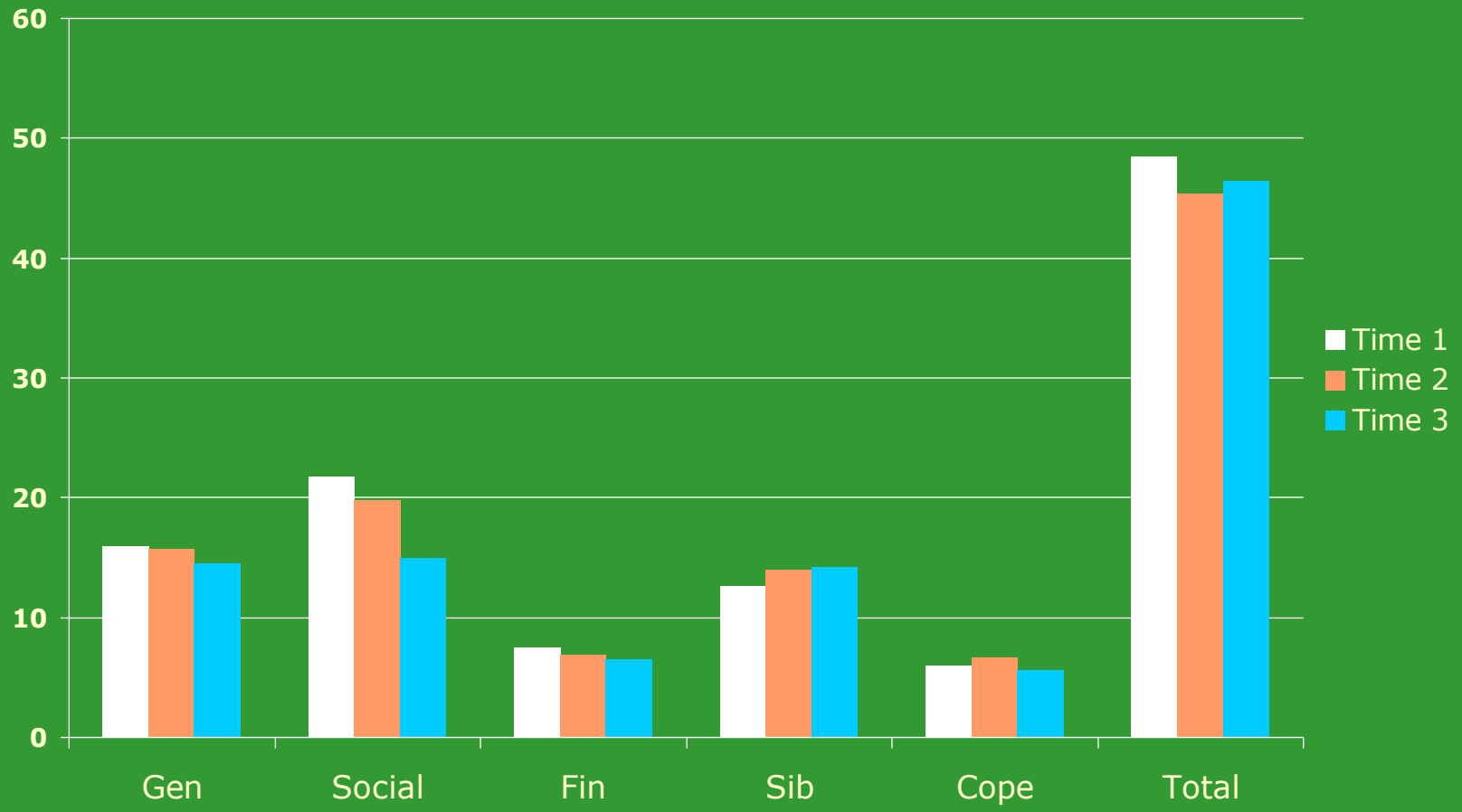
- Impact of Illness Scale (Stein & Reissmann, 1980): Total impact α = .9101, social α = .8278, sibling α = .80, general α = .52, financial α = .7303, coping α = .62.

- MSPSS (Zimet et al., 1988): Total support α = .9603, family α = .946, friend α = .9494, significant other α = .9577.

Impact of Illness on Family Scale: Mean scores Time 1, 2 & 3

Scale	Time 1	Time 2	Time 3	Range
General	16	15.8	14.5	6 – 24
Social	21.75	19.8	15.0	9 – 36
Financial	7.571	6.875	6.5	4 – 16
Sibling	12.6	14.0	14.25	6 – 24
Cope	6.0	6.714	5.6	4 – 16
Total	48.5	45.4	46.5	19 – 76

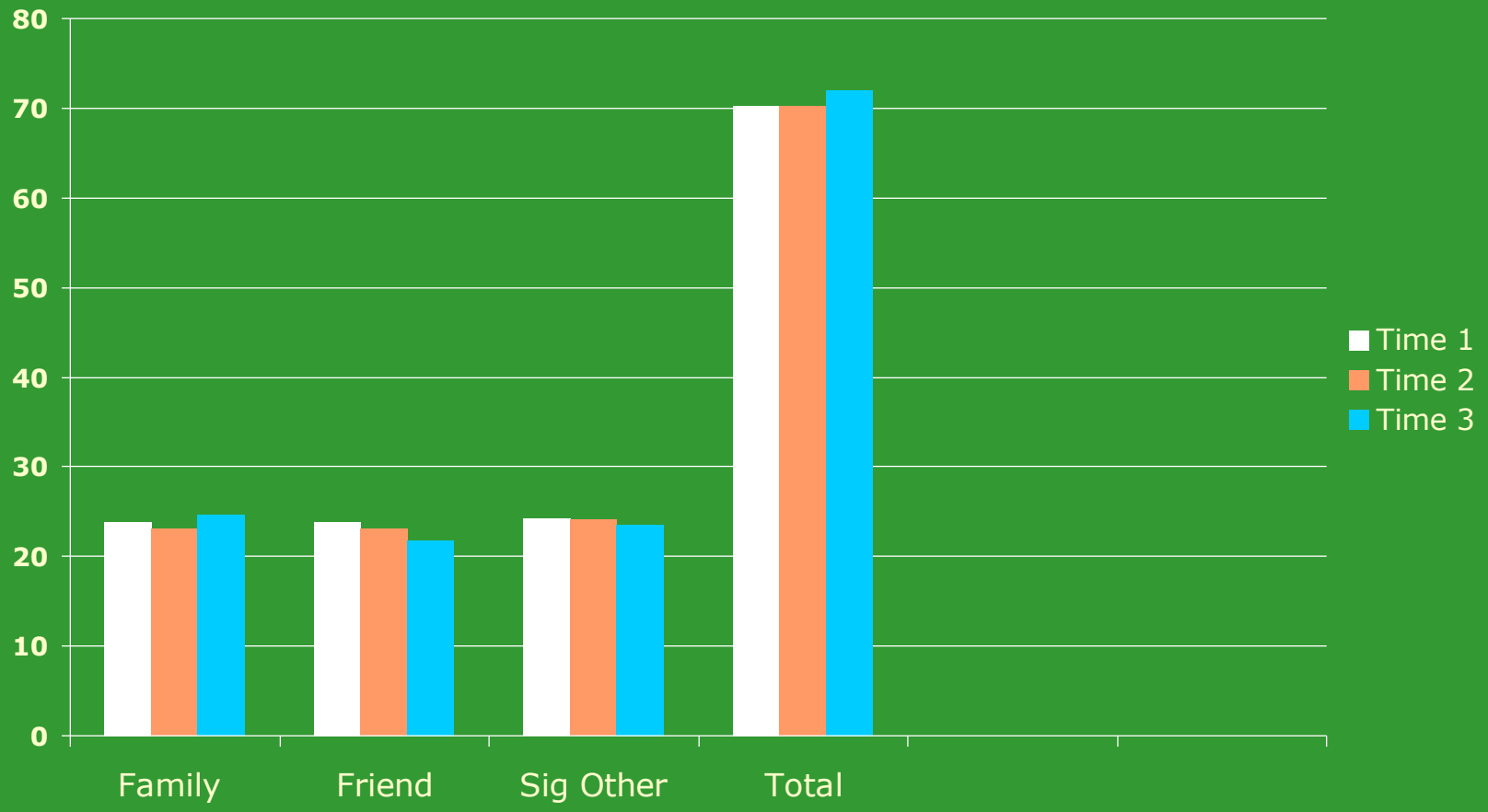
Impact of Illness on Family Scale (Time 1, 2 & 3)



Multidimensional Scale of Perceived Social Support: Mean scores Time 1, 2 & 3

Scale	Time 1	Time 2	Time 3	Range
Family	23.8	23.13	24.6	7 – 28
Friend	23.85	23.12	21.83	7 – 28
Sig Other	24.25	24.12	23.6	7 – 28
Total	70.28	70.2	72.0	12 – 84

Multidimensional Scale of Perceived Social Support: Time 1, 2 & 3



Preliminary qualitative findings: Main themes (Time 1)

Experiences of illness:

- Initial shock

"it was like a bomb exploded in the family"

- Worry and fear

- Impact on family dynamic (separation of family for long periods of time, changes in family member roles, impact on individual family members, impact on social life of family)

" Major difficulty in maintaining a "normal" family life. Juggling a baby and two older children with regular hospital appointments and work is a constant strain"

- Importance of support

Preliminary qualitative findings: Main themes (Time 2)

- **Feedback for Barretstown's programme:** Fun & enjoyment, activities, the staff, family time together, meeting families in same situation, issues affecting younger children

"Everybody at Barretstown put so much effort into what they did for the children, and also for the parents. It was wonderful".

- **Impact of programme:** Fun/memories, importance of family time, social participation, increased awareness of other family members, sense of perspective

"I think we learned that life can go on.."

Preliminary qualitative findings: Main themes (Time 3)

Continuing impact of time at Barretstown?

- importance of family time
- increased recreation & leisure participation

" We learned that its good to have fun together both as a family and as individuals. We're trying to put that into practice"

- less overprotective towards ill child
- increased awareness of strengths (both of individual family members and of family unit)

"she (child diagnosed with cancer) saw the way other kids were getting on with it and it was a real kick start for her"

Preliminary conclusions

Impact of Barretstown's programme

Insight into families' experiences of illness

Reliability of standardised measures

Direction of mean scores (T1 – T2 – T3)

Need for comparison data

Plans for on-going study

- Barretstown families
  - Spring & Autumn 2006
  - Spring 2007
- Comparison families – currently being sourced through Our Lady's Hospital for Sick Children in Crumlin
- Addition of Time 4 point (12 month follow-up) for Comparison families

- Thank you
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