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A family based intervention to promote adjustment in siblings of children with cancer: a pilot study.

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Conflict of Interest Statement

We declare that there are no potential sources of conflict of interest.

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Ethics

This study was submitted and approved by the National Ethics Committee in Northern Ireland and from the Ethics Committee of the Belfast Health and Social Care Trust.

Background

A recent systematic review suggested that whilst positive outcomes are evident for some siblings of children with cancer (e.g. related to post-traumatic growth), a significant subset experience negative emotional reactions, isolation, school difficulties and reduced quality of life.[1] Proposed new standards of care in paediatric oncology emphasise extending psychosocial care to family members of the child with cancer.[2] The literature indicates that family functioning is a significant predictor of outcomes for the chronically ill child, suggesting that family focused interventions are warranted[3].

Few studies of such interventions exist. Historically, Barerra's sibling only group intervention,[4] based on cognitive – behavioural principles, showed promise in reducing emotional distress. Kazak's Surviving Cancer Competently Intervention Program[5], a cognitive-behavioral and family therapy intervention originally designed for adolescent survivors of childhood cancer and their families, found improvements in terms of level of anxiety and post-traumatic stress reactions. Lobato's integrated psychoeducational sibling – parent group[6] found improvements in both knowledge and feelings of "connectedness". The present family-focused intervention was informed by the updated evidence base for effective

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psychosocial interventions across different chronic illnesses[2,3]. Research suggests that interventions which include problem solving therapy, narrative therapy and psycho-education are effective in enhancing family communication.[3,7] Promoting more effective family functioning, coping and resilience is the fundamental aim of these interventions and we tested such a programme as described below (a) for feasibility and acceptability and (b) to explore whether findings of clinical changes were promising in a pilot study.

Methods

Participants and recruitment

Parents and siblings of children who were being treated for cancer were recruited by their medical consultants through a paediatric oncology centre in the UK. Inclusion criteria included (a) having a child (0 – 18 years) currently undergoing treatment for any cancer type, who was at least 3 months post-diagnosis and (b) having at least one other child (7 – 18 years) also willing to participate in the study. Exclusion criteria included (a) palliative treatment only in the child with cancer and (b) any developmental or neurological disorders in the sibling.

Sixty-four eligible families were identified by the consultant oncologists and haematologists. Forty-two expressed interest. Of these, twenty-seven were not able to participate due to scheduling difficulties and family priorities at that time in relation to the child with cancer. Fifteen families signed the consent forms and were subsequently contacted by the researchers. Twelve families participated in the intervention (online supplementary Figure 1). The final sample included 17 siblings from 12 families (7 – 17 years), 12 mothers and 7 fathers. No sibling participants were in the clinical range on a depression and anxiety screening measure at baseline. Further demographics are outlined in online supplementary Table 1.

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Design and measures

A single-group design was employed with measures taken pre-intervention (T1), 4 (T2) and 12 (T3) weeks post-intervention. The effect of an intervention targeting family processes, as outlined below, was expected to take some time to impact on outcomes. These follow-up times were judged optimal to provide an indication of whether such had occurred. The study had passed both the National and Local Ethical Committees Reviews. Two waves of recruitment and intervention took place (October – December 2010; July 2012 – April 2013) with the 12 week follow-up occurring only following the second wave (hence reduced numbers for the 12 week data).

Standardized measures completed by the siblings included:

- Beck Youth Inventory (BYI)[8] – *self-concept, anxiety* and *depression subscales*.
- Resiliency Scales for Children and Adolescents (RSCA)[9] – *resources* and *vulnerability* indices.
- Children's Coping Strategies Checklist (CCSC)[10] – *active coping, positive cognitive restructuring, avoidance* and *support seeking subscales*.

The Psychosocial Assessment Tool – 2 (PAT – 2)[11] was completed by mothers to measure overall psychosocial risk within the family. Both parents and siblings completed a bespoke questionnaire which explored participation experience of the intervention in open ended format (see online supplementary Document 1). Further psychometric details of these measures and constructs assessed, related to the aims of the intervention, are outlined in online Supplementary Table 2.

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Intervention

A one day workshop format was used as this had been shown to be effective in previous paediatric interventions at this centre[7] whilst minimizing the attrition that comes with several group sessions over many weeks. This was consistently delivered by a clinical psychologist and a play specialist for the siblings' groups and a different clinical psychologist for the parents' groups. The siblings' groups were formed based on age (younger children 7-11 and teenagers 12-17) and the therapeutic activities were adapted accordingly. A family friendly programme manual was developed for participants to summarise the programme content and to promote maintenance of gains. Interventions utilised problem-solving therapy with respect to worries and fears, narrative techniques and interventions to assist meaning making and emotional processing - both in separate parent / sibling groups and then together to enhance communication - and medical education and psychoeducation. Details of the intervention are outlined in online Supplementary Table 3.

Analyses

No inferential statistics were used as this was a pilot study; rather effect size (ES) changes were calculated to establish clinical significance between baseline, 4 and 12 week follow-ups. An ES greater than 0.2 was indicative of a small change, 0.5 a medium effect and 0.8 a large change. Feasibility and acceptability were assessed through uptake rates, retention and feedback on the experience of participation from participants. Participants' feedback were collected and a thematic analysis was conducted to analyse the data.

Results

The participation rate was low (19% of families invited). However, a further 30 / 64 of families expressed an interest in participation but felt unable to do so for the reasons outlined

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in online Supplementary Figure 1. All participants completed the intervention and 11 / 17 siblings and 13 / 19 parents completed follow-up measures at 4 and 12 weeks post-participation. All indicated that they would recommend the programme to other families. On a Likert scale of 0 - 10 all participants rated the intervention as at least “very helpful” with Likert scores ranging from 7 – 10. Themes from open-ended qualitative feedback from parents included an increased understanding of siblings’ needs, positive changes in family communication and a sense of communality of family experiences. Sibling themes included the learning of new problem-solving strategies, sharing experiences with others and a better understanding of their own and sibling's needs.

Table 1 summarises changes on each of the outcome measures utilized. Little change was evident on BYI subscales of *anxiety* or *depression*, although the effect size approached moderate significance on *self-concept* between T1 – T2. Changes related to resilience, however, were suggested by moderate effect size increases on the *Resources* subscale of the RSCA between both T1 – T2 and T1 – T3 and reduced scores on the *Vulnerability* index between T1 – T3. Small effect size increases were observed on the *Active Coping* and *Positive Cognitive Restructuring* subscales of the CCSC. However moderate – large effect size reductions were observed on the *avoidance* and increases on the *support seeking* subscales of the same measure. Finally, between T1 – T3 a moderate effect size reduction was evident on the *Family Psychosocial Risk* score on the PAT – 2.

TABLE 1

Discussion

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A new one-day family focused intervention for siblings of children with cancer is presented. Key elements focused on meaning making through narrative strategies, problem solving therapy and psychoeducation, within a systemic framework.

The programme proved feasible in terms of the programme delivery and retention of participants. However, there were significant challenges in terms of recruitment onto the programme, which suggests the need to conduct an analysis of the barriers to participation. Given the limitations it may be helpful to replicate the study in a larger centre or using multiple sites in the future.

The acceptability of the programme, to both parents and siblings, was good with all participants suggesting they would recommend it to others. Many of the qualitative themes echoing programme objectives. Thus, reports of improved understanding, family empathy, communication and the learning of new problem solving strategies were noted and reflect areas of need identified in the literature[1,2].

In terms of pilot outcomes, gains were most evident in siblings in terms of a reduction in self-perceived vulnerability and avoidance strategies and increased use of social support and other available resources. A reduction in overall family psychosocial risk was reported by mothers. These gains directly relate to the adjustment difficulties and needs identified in siblings in the literature.[1,2]

Limitations

- The uptake rate was low. Suggestions to improve recruitment for the future may be to offer the treatment as an integral part of the standard care for all families and to have testimonials of families who participated in the study as part of the information sheet.
- Without a control group, we cannot discount that the gains may have been due to the natural course of improved adjustment. Although the themes evident in the qualitative

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evaluation suggested the participants saw a direct link to the intervention. These promising findings now point to the relevance of a controlled trial.

- Two siblings from the same family were present in five of the families. This compromises independence of cases in analyses and should be reviewed in a future controlled trial.

Key Points:

- An innovative family focused intervention for siblings of children with cancer and their parents is described and pilot findings reported.
- The intervention combined systemic, narrative and problem-solving strategies.
- The programme proved feasible in terms of delivery, completion and retention.
- Significant challenges were highlighted in terms of recruitment and participation rates.
- Promising outcomes in relation to sibling and family adjustment were observed.

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Table 1: Means, standard deviations and effect size changes

Outcome measures	Mean (SD) T1	Mean (SD) T2	Mean (SD) T3	T1 -T2	T1 -T3
Beck Youth Inventory	n = 17	n = 13	n = 8		
Self Concept	45.76 (9.437)	49.54 (9.210)	47 (8.97)	0.41	0.13
Anxiety	45.41 (8.47)	45.38 (6.16)	46.25 (6.60)	- 0.004	0.11
Depression	46.94 (8.93)	45.38 (8.16)	46.50 (6.80)	- 0.18	-0.05
Resiliency Scales for Children and Adolescents	n = 12	n = 8	n = 8		
Resources	39.25 (13.58)	46.13 (12.75)	47.75 (14.74)	0.52*	0.60*
Vulnerability	56.33 (14.30)	52.50 (9.40)	49.50 (7.95)	- 0.32	- 0.60*
Children's Coping Strategies Checklist	n= 11	n= 8	n= 8		
Active Coping	2.13 (0.45)	2.34 (0.59)	2.27 (0.49)	0.40	0.30
Positive Cognitive Restructuring	2.26 (0.48)	2.49 (0.67)	2.37 (0.51)	0.40	0.22
Avoidance	2.64 (0.31)	2.45 (0.57)	2.28 (0.21)	-0.41	-1.36**
Support seeking	1.68 (0.51)	2.07 (0.56)	1.96 (0.58)	0.73*	0.51*
Psychosocial Assessment Tool 2	n = 12	n = 10	n = 6		
Family Psychosocial Risk	1.34 (0.46)	1.34 (0.57)	1.11 (0.32)	0.01	- 0.58*

T1: Pre-intervention; T2: 4 weeks post intervention; T3: 12 weeks post intervention; * moderate effect size d ≥ 0.5; ** large effect size ≥ 0.8

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