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The Strong Parents-Strong Children Programme: parental support in serious and chronic child illness

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Abstract

Aim To determine the effectiveness of an intervention programme developed to help parents manage serious child illness.

Method Information from previous research about parents' stress of managing their children's serious illnesses, plus their wishes for what to do about it, were used to develop a behavioural intervention to be used with groups of parents with seriously ill children. The 6-week programme, called 'Strong Parents-Strong Children', was tested using a wait-list control design, and evaluated by standardised and researcher-developed psychological measures.

Results Several significant post-test changes in healthier directions were found for the study group, compared with the control group. Additionally, the group process and session helpfulness received positive appraisals, personal goals were attained at high levels, and most participants said they would recommend the programme to others in similar situations.

Conclusions The programme appears to have a significant and positive impact on the parents of seriously ill children.

In serious child illness, the parent role is an integral part of the treatment process, and is critical in co-ordinating all that is happening for the child. Managing these illnesses adds considerably to the stresses of normal child-rearing. Potential risk to maternal mental health is documented in the literature.[1,2]. In mitigation of these risks, responsive social support (including support provided by professionals)[3] is helpful. When parents feel confident in working alongside professionals, they are better able to collaborate in ensuring their sick child's quality of life.

This research is the first in New Zealand to investigate the effectiveness of a parent-centred intervention where the focus is support, learning of skills, and stress management for those with children with serious illness and special needs.

The programme described here, entitled 'Strong Parents-Strong Children', helps parents manage illness-related stresses and learn advocacy and practical skills within a child development framework. The primacy of the parent role in helping to optimise their sick child's development (particularly where there are disabling sequelae) formed the rationale for such an intervention.

This paper involves a test of the efficacy of this programme with parents of children referred from the three main hospitals in Auckland.

The intervention programme

The Strong Parents-Strong Children programme consists of six once-weekly sessions. The content focuses on the common stresses faced by parents with seriously chronically ill children, and was obtained from two sources. One was a series of preliminary studies undertaken by the first author. This involved interviewing 40 parents, including those of Maori, Cook Island Maori, and Fiji Indian origin, plus paediatricians and charge nurses, from which a ranking of parental stresses was derived. The second source was from the current psychological literature describing optimal approaches relating to child development and stress management.

Draft versions of the programme were initially trialled over a year with 12 parents, and the version tested here evolved from this process. Each of the six sessions consists of three equal components: input from the facilitator, group discussion, and review of weekly 'homework' assignments. Through reiteration of principles and discussion of examples, opportunities are provided for strengthening parent understanding and self-help. In this research, the first author (HJ) was the programme facilitator. Her role was important since she had a similar history as a parent, and hence to some extent was an 'empathetic peer'.

The session content and process were as follows:

- **Session 1—**This session was introductory, with the facilitator (HJ) beginning by introducing herself and her background as well as her involvement in this area (including what she had learned from other parents in previous research). Pre-course research measures were completed by participants, after which they introduced themselves and shared child illness information; ground rules for this and the following sessions were established. The group processes of learning skills to deal with illness-related stress, personal goal-setting and weekly-reviewed homework were outlined, and the theme of parents taking care of themselves was emphasised. Information about community support was also provided.
- **Session 2—**Strategies for ensuring time to themselves and the importance of learning relaxation skills were discussed. A Mental Health Foundation relaxation CD[4] was provided for home practice. The concept was introduced of the common cognitive tendency to 'catastrophise' under stress,[5] including how to deal with this through self-talk (with examples taken from the facilitator's and other participants' own experiences).
- **Session 3—**Here the theme was getting desired information from relevant health professionals. Suggestions were made regarding appropriate skills and strategies, and were reinforced with role-plays. The need for parents to have information from professionals properly documented was examined, and their own important role as advocates and providers of information to others was emphasised.
- **Session 4—**This session focussed on the parents' unique role, and the expertise that they already have in caring for their sick child. The need to have siblings involved and not be overlooked was emphasised. Strategies for child-friendly and consistent behaviour management were covered.
- **Session 5—**Domestic organisation in terms of setting priorities in daily illness and household management was discussed. Other matters included accessing family

and wider agency support outside the household, benefits of shared parenting, and the importance of maintaining normal family activities. The value for the ill children of maintaining their existing friendship links and school contacts was also addressed.

- **Session 6—**This final weekly session looked at the family's way of operating once the acute phase of the illness process was over. The emphasis was on 'normalising' family process and ethos, and on helping the child to manage their own health where feasible. Participants' future plans were shared, the progress on each person's course goals set in Session 1 were discussed, and a follow-up session date arranged. Finally, post-course research measures were completed.
- **Follow-up Session—**This took place 6 months after Session 6. Participants reviewed their child's progress, their own wellbeing, and the usefulness of the strategies they had learned in the course. Parents' changed perspectives were shared, and longer-term and future goals discussed. Plans for keeping in touch were made. Follow-up measures were completed.

Note: All sessions took place in the University of Auckland School of Medicine, Grafton, Auckland.

The participants (parents)

Fifty-eight parents whose children had current serious health conditions participated in the study: 41 in a study group and 17 controls. Although no parents had evidence of marked psychosocial pathology, all were experiencing the intense stress that is associated with having a child with serious health impairment.[6.] Table 1 shows the characteristics of the parents who participated.

Table 1. Study group and controls: demographic characteristics of parents

Variable		Study Group (N=41)		Control Group (N=17)	
		Mothers (N=38)	Fathers (N=3)	Mothers (N=13)	Fathers (N=4)
Parenting	Shared	30	3	9	4
	Separate	8	0	4	0
Age range (yrs)	21–30	4	0	2	0
	31–40	22	2	7	3
	41–50	12	1	4	1
Ethnicity	Maori	0	0	1	0
	Pakeha*	38	3	12	4
Education	Secondary	13	0	6	1
	Tertiary	22	3	5	3
	Student	3	0	2	0
Employment	No	18	0	10	0
	Full-time	3	3	0	4
	Part-time	17	0	3	0

*New Zealand European.

The children

Table 2 shows that the most common diagnoses among the children were cancers, which included brain tumours, neuroblastomas, leukaemia, osteosarcoma, Burkitt's lymphoma, and Hodgkinson's disease. Other illnesses included cystic fibrosis, haemophilia, diabetes mellitus, severe epilepsy, coronary heart disease, supraventricula tachycardia, restrictive cardiomyopathy, infantile stroke, neurological impairment, cerebral palsy, a liver transplant, Pierre Robin syndrome requiring surgery, the ongoing construction of the missing part of a child's chest wall, congenital trachea, oesophageal fistula receiving periodic critical care, Down's syndrome (with diabetes), and chiachondroplasia. Ten children were receiving educational support.

Referrals

Referrals came equally from hospital charge nurses on the advice of paediatricians, and from self-referrals, consequent on parents learning about the groups from support organisations and from other research participants. Criteria for entry to the study were parents who were normal everyday parents, willing to be randomly assigned to either a study or to a control group. Charge Nurses, in discussion with paediatricians, told parents who met these criteria about the research and parents who were interested contacted the researcher. Therefore this was a convenience sample.

Methods

Experimental design—A wait-list design[7] was used. Figure 1 shows the design from initial intervention to the 6 months follow-up. The study and control groups ran for 6 weeks in parallel. The study group had measures taken at weeks 1 and 6, and the control group at weeks 7 and 12. (The control group later received the intervention but their treatment data are not included here.) Follow-up sessions were held for both groups 6 months after their respective last group sessions.

Participants were allocated randomly to study and control groups by drawing names from a container. It was felt there was an ethical requirement to intervene immediately, which meant as many parents as possible were included in the intervention group. Forty-one participants were chosen and distributed between seven study groups, ranging in size from five to seven participants. Eligible parents were informed that they would all receive the programme but that those allocated randomly to a control group would receive the intervention later.

Measures—The principal measure was the Parent Self-Rating Scale (PSRS)[8], developed by the first author (HJ), consisting of a set of 12 analogue scales measuring participants' knowledge and skills related to coping with their children's illnesses. In addition, five standard psychological tests were used. These were the Affectometer 2[9] (wellbeing and happiness), the Life Orientation Test[10] (general optimism), the Family Environment Scale[11] (10 dimensions of family life), the COPE[12] (general coping), and the Short Form of the State-Trait Anxiety Scale (STAI)[13] for general anxiety. Overall, the component parts of these 6 measures provided 38 variables for analysis.

Goal-setting was also used as a measure. This involved participants formulating short-term (end-of-course) behavioural objectives (e.g. attend to own health needs, re-discover friends, do short computer course, lessen anxiety, be assertive over child's needs) and longer-term (six months) behavioural objectives (e.g. ensure successful transition back to school, achieve child self-management of condition, ensure fun times, complete training courses). Achievement on a five point scale ('fully achieved' to 'not attempted') was assessed.

Finally, participants' ratings were taken using a four-point scale for variables of feeling supported, meeting other parents, cohesiveness of group, and leadership style. Five point ratings were taken for session helpfulness and whether or not they would recommend the programme to other parents. Attendance was also recorded.

Statistical analyses—The observed means and standard deviations are reported for the two groups both before (pre) and after (post) the 6 week intervention period. The scores of the control group and intervention group after the 6-week intervention period were compared using a general linear model which included the score at baseline, treatment (active, maintenance or completed), illness type (cancer or otherwise), months since diagnosis (up to 6 months, 6 or more months), and age group (0–12 years, 12–17 years).

The test statistic and its associated P value for the difference between the two groups are reported. To determine the impact of the three levels of treatment on outcomes, a Tukey-Kramer test was done post hoc across both study and control groups. For the group that underwent the active intervention during the study period, their 6-month scores are also reported.

Figure 1. Timeframe of study and control group

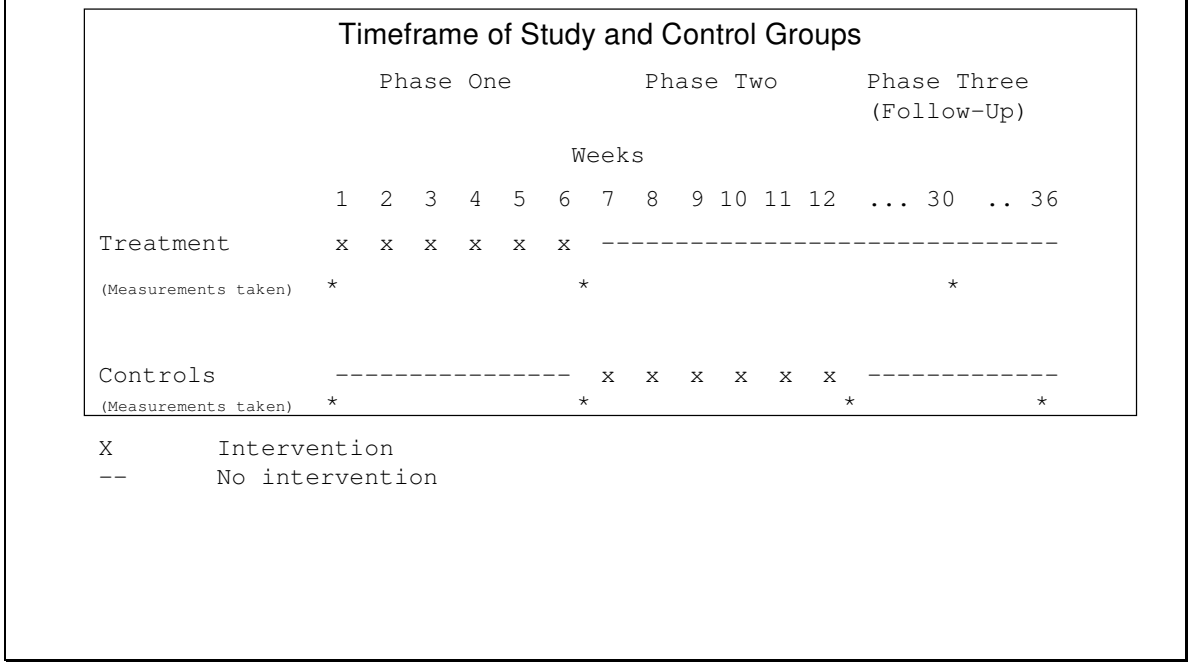

Table 2. Characteristics of the 54 children and their illnesses

Diagnosis	N	Gender		Age	Time since diagnosis		Treatment status		
		Male	Female	Mean (yrs)	Mean (yrs)	Range (yrs)	Active	Maintenance	Completed
Cancers	25	12	13	8.1	1.6	16	13*	1†	11
Diabetes mellitus	7	5‡	2	8.8	1.9	5		7	
Severe epilepsy	5	1	4	7.8	6.9	13	1	4	
Cystic fibrosis	2	2	0	5.4	5.1	8		2	
Heart disease	4	2	2	5.1	4.3	2	2	2	
Liver transplant	1	1	0	3.1	3.0		1		
Neurological	3	3	0	9.1	5.6	9		2	1
Haemophilia	1	1	0	6.5	6.5			1	
Surgical repair	3	1	2	5.4	4.7	10	1	1	1
Diagnosis awaited	3	2	1	1.1			1§	2**	

*1 child was being considered for a second bone marrow transplant; †Receiving alternative treatment; ‡Including 1 child also diagnosed with Down's syndrome; §Hospitalised with mother for 1 year; **1 at GP and 1 at Starship Clinic.

Table 3. Variables showing significance on the Parent Self-Rating Scale, Affectometer 2, Family Environment, COPE, and STAI: analyses of covariance of variables post-test (n=41) and paired t-tests from post-test to follow-up (n=33)

PARENT SELF-RATING SCALE		Pre-test	Post-test	Comparison of change		6-month follow-up
		Mean (SD)	Mean (SD)	F (1,50)	P value	Mean (SD)
Optimistic will cope	S	44 (32)	72 (25)	13.5	p<0.001	68 (29)
	C	35 (29)	45 (25)			
Feeling calmer	S	57 (30)	73 (23)	17.5	p<0.001	68 (25)
	C	46 (25)	45 (21)			
Stronger as parent	S	61 (31)	81 (18)	14.8	p<0.001	78 (23)
	C	44 (29)	53 (27)			
More accepting illness is random	S	57 (32)	78 (21)	19.5	p<0.001	74 (26)
	C	42 (33)	47 (30)			
More included in clinical decisions	S	62 (28)	82 (18)	21.9	p<0.001	78 (25)
	C	54 (26)	57 (24)			
Able to get needed information	S	61 (28)	83 (16)	24.3	p<0.001	80 (24)
	C	60 (31)	60 (25)			
Advocating for child with professionals	S	65 (26)	85 (15)	11.4	p=0.001	80 (21)
	C	61 (28)	68 (22)			
Better organised	S	52 (32)	75 (23)	7.9	p=0.007	73 (26)
	C	52 (31)	55 (24)			
Better able to manage change in our lives	S	56 (30)	76 (23)	9.3	p=0.004	76 (24)
	C	46 (29)	52 (24)			

AFFECTOMETER 2		**Pre-test**	**Post-test**	**Comparison of change**		**6-month follow-up**
Wellbeing	S	1 (1)	2 (2)	10.9	p=0.002	2 (1)
	C	1 (2)	1 (1)			
Happiness	S	4 (2)	5 (1)	8.3	p=0.006	6 (1)
	C	4 (1)	4 (1)			
FES		**Pre-test**	**Post-test**	**Comparison of change**		**6-month follow-up**
Cohesion	S	7 (2)	8 (1)	6	p=0.018	7 (2)
	C	6 (3)	7 (3)			
COPE		**Pre-test**	**Post-test**	**Comparison of change**		**6- month follow-up**
Emotional support	S	11 (4)	13 (3)	12.1	p<0.001	12 (3)
	C	11 (4)	11 (3)			
Growth / re-interpretation	S	12 (2)	13 (2)	6	p=0.017	13 (2)
	C	10 (3)	10 (3)			
Planning	S	13 (3)	13 (2)	4.6	p=0.038	13 (3)
	C	11 (2)	10 (3)			
Information	S	11 (3)	12 (3)	7.1	p=0.010	12 (3)
	C	9 (3)	9 (3)			
STAI		**Pre-test**	**Post-test**	**Comparison of change**		**6-month follow-up**
General anxiety	S	14 (5)	12 (4)	4.6	p=0.036	12 (4)
	C	15 (4)	14 (4)			

PSRS=Parent Self-Rating Scale; FES=Family Environment Scale; STAI=State-Trait Anxiety Inventory.

Results

The overall attendance rate was 93%. There were four dropouts, all of whom left for reasons unrelated to the course itself (e.g. left Auckland): three after the first session and one after the second session.

As stated previously, overall, 38 variables spanning the 6 measures were subjected to analyses. Table 3 shows the 17 variables that were statistically significant at the 5% or better level of significance. All the significant results are in a 'healthy' direction. As can be seen, these improvements were on 9 variables of the PSRS (reflecting participants' self-perceived improvements in effectiveness, stress management skills and role as parents), and 8 variables from the standard psychological tests (representing improvements in wellbeing, family cohesion, anxiety levels and overall coping).

The Tukey-Kramer analysis of the 3 categories of child treatment status (active, maintenance, completed) showed that for 10 of the PSRS variables, as well as for 'Affectometer 2' and 'STAI general anxiety' scores, parents in both the study and control groups with children in *active* treatment had less healthy mean scores at post-test ($p<0.05$) than those with children who had completed treatment or were on maintenance treatment.

Many of the children under active treatment had cancer. Similar analyses showed that parents with younger children (0–12 years) did generally better on the PSRS in terms of organisation and coping than parents with children entering adolescence (12–17 years).

Analysis of the study group's 6-month follow-up data on the PSRS and the standardised measures showed no significant reductions in any mean scores compared with post-test scores, thus indicating overall maintenance of the positive changes made during the course .

With regard to personal goal-setting, a total of 244 goals were set by the 41 participants in the study group. At post-test, 88% of these goals were rated at the top two of the five achievement levels ('fully achieved or 'good progress'). At 6-month follow-up (N=33), this figure was only slightly lower at 86%, thus suggesting maintenance of course-related goal attainments.

On judgements of group process, 98% of study group parents rated the groups as 'very' or 'most' supportive; 95 % of parents rated meeting other parents as 'very' or 'most' helpful; and 81% of parents rated the groups as being 'very' or 'most' cohesive. The facilitator's style was rated by 93% as 'very' or 'most' empathic, and 89% would 'definitely' recommend the programme to other parents in similar situations.

Discussion

The preliminary research that preceded the study reported had shown that children's serious illnesses were having a major impact on their parents' daily lives. Family routines had changed and parents had significant concern for their ill children's future.

After experiencing the Strong Parents-Strong Children programme, participating parents reported significant improvements in several areas: they felt better able to manage several aspects of their child's illness. They felt empowered to cope with what lay ahead; better able to get information they wanted; stronger as advocates for their children; and affirmed in their own expertise in caring for their children. Their levels of wellbeing and happiness were also significantly higher than when they started the programme, and their anxiety levels decreased. They also perceived their families to be more united; they felt more emotionally supported; and they were better able to plan and deal with stress.

In addition, they were able to achieve most of the individual behavioural goals they set for themselves, which included such matters as increasing their levels of exercise, relaxing, having time for themselves, attending to their own health needs, and meeting their children's educational needs. At 6-months follow-up, most or all of these gains seem to have been maintained.

Overall, parents appeared very much to enjoy their participation in the programme and how it was run, and would recommend it to others in similar situations. One interesting finding relates to the fact that parents whose children were in active treatment appeared to respond less positively on some measures, compared with those whose children's treatment was completed or at a maintenance level. This would support the intuitive notion that that parents whose children are actively undergoing treatment may be more concerned with (and vulnerable to) the stresses of what is happening with their children than those who have passed that stage.

Most of the participants in this research were mothers, and the risk to maternal mental health of having a child with a serious illness is well documented in the literature. This study, therefore, can be seen as a contribution to the general area of maternal mental health, as well as to aiding the physical health of the children through their parents' increased efficacy and confidence. The role of social support, as well as the actual skills learned, should not be underestimated here, since the role of the group and the facilitation by a 'peer' were very important aspects.

From a medical research perspective, this research is notable for the fact that it gives the primary voice and attention to those studied—the parents. Professionals clearly have a critical support role to play. However, the key to the success of this programme is seen in the fact that it was largely determined by, and empowering for, the parents concerned.

Overall, this research is a first of its kind in New Zealand, and possibly the World, and shows that a parent-determined programme of this nature can have much to offer in an area as difficult and distressing as serious child illness.

Note: After the completion of this research, a charitable trust was set up by the first author to continue the programme at no cost to parents, which was done in a variety of hospital and community settings around Auckland. The programme is currently in recess.

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