Chapter 9

CBT For Carers Of Children With Intellectual Disability And Challenging Behaviour: Two Cases

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Background

There is an established link between challenging behaviour in children with intellectual disability and parent stress. Two cases are presented in which a brief course of manualised Cognitive-Behaviour Therapy to reduce parent stress led to a reduction in each child's reported challenging behaviour.

Introduction

When responding to a referral for behaviour support for a child with an intellectual disability and challenging behaviour, it can be difficult for the clinician to know where to start. Clinicians are often confronted with a range of carer issues concurrent to the child's behaviour, including parental or other interpersonal conflict (Nicoll, Dowling, & Thomas, 2004); financial hardship; social isolation; challenging behaviours in siblings (Strohm, 2002); and longer-term emotional or interpersonal impacts of the child's initial diagnosis on family members (Poehlmann, Clements, Abbeduto, & Farsad, 2005). Evidence has emerged that the impact of child challenging behaviour on parents is greater when the child has an intellectual disability (Baker et al., 2003). This challenging behaviour, in combination with these other issues, may thus have a range of impacts on the parents.

Emerson et al.'s (1988) definition of challenging behaviour hints at the nature of these impacts. They define challenging behaviours as '…behaviours of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which seriously limits the person's access to ordinary settings, activities, services, and experiences' (p.16). Two impacts implied by such a definition are physical injury to carers, and social isolation for both the child and the carer.

Traditionally, carer stress or distress is appraised by the clinician as a potential barrier to intervention, or perhaps as a basis for prioritising one referral over another. Given the association between child challenging behaviour and carer stress, there may be merit in the clinician directly treating carer stress, alongside the child's behaviour.

Much of what a child with a disability brings to their family is undoubtedly positive (e.g., Taunt & Hastings, 2002; Nicoll, Dowling, & Thomas, 2004). Yet there is now ample evidence that caring for a child with intellectual disability and challenging behaviour, while being rewarding, can also lead to stress, depression or other psychosocial difficulties for the parent, as well as the child, often persisting throughout and even beyond the child's lifespan (Hauser-Cram et al., 2001; Nicoll, Dowling, & Thomas, 2004). A correlation between behaviour problems in children with intellectual disabilities and parental distress has been established for over thirty years (e.g., Dorner, 1975; Quine & Pahl, 1985; Tew & Lawrence, 1975). However, correlation does not demonstrate causation. What, then, is the nature of the link between child challenging behaviour and parental stress or distress? Recent findings by Beck, Hastings Daley and Stevenson (2004) add to the growing empirical evidence supporting the anecdotal reports of clinicians, that the presence of challenging behaviour in children with intellectual disability positively predicts parental stress (e.g., Tomanik, Harris and Hawkins, 2004; Hastings, 2002).

While there is both intuitive and empirical support for the notion that challenging behaviour is stressful for carers, evidence to support the reciprocal hypothesis that carer stress leads to child challenging behaviour remains sparse. According to Hastings and Beck (2004), while 'in general terms' such an effect is likely, and that there is evidence for such an effect in non-disability literature, 'there are

few studies within the intellectual disability literature to offer direct support for a relationship between parental stress and parenting behaviour' (p. 1338). Hastings (2002) has nevertheless provided a model for an 'interrelation' of child behaviour problems, parental stress and parenting behaviour. The model, reproduced in Figure 9.1, depicts his proposal that, '…parents and children reciprocally affect each other, children's behaviour problems lead to stress in parents, and parents under stress adopt certain parenting behaviours that tend to reinforce the child's behaviour problems' (p.151). Woolfson and Grant (2006) have contributed preliminary empirical evidence in support of Hastings' model, concluding that the impact of challenging behaviour on parental stress is mediated by parenting style.

[Insert Figure 9. 1 here].

Hastings' model allows for three possible points of intervention for clinicians seeking to assist a family with a child with intellectual disability and challenging behaviour. These points of intervention are (1) the child's behaviour per se; (2) parental stress; and (3) parenting style. Efficacious interventions directly targeting the first of these, the *child's behaviour*, will not be canvassed in detail here. The dominant paradigm for such interventions currently appears to be a combination of Positive Behaviour Support strategies (Koegel, Koegel & Dunlap, 1996; McVilly, 2002), and psychoactive medications (McVilly, 2002). The role that parents play in these interventions is typically as program implementers. The third potential intervention point, *parenting style*, is most commonly addressed as a subset of any comprehensive Positive Behaviour Support Program under the label of 'parent training' (e.g., McVilly,

2002; Plant & Sanders, 2007). *Parental stress* is not directly targeted in most Behaviour Support Programs, simply because the child, not the parent, is seen as the client. Parental stress or distress is typically addressed indirectly if at all. This may occur during social gatherings, support planning meetings, or parent training/education sessions. Case workers or clinicians may find themselves becoming involved in counselling-style conversations with parents seeking an understanding, and uncritical ear to talk to about their day-to-day challenges. There is yet to be a formal exploration of the efficacy of this 'incidental counselling' in alleviating parent stress or distress.

Parent stress may also be more directly alleviated with attendance at carer support groups, or through specific clinical interventions. The benefits of carer support groups are well documented (e.g., Adamson, 1972; Gavidia-Payne & Hudson, 2002; Greaves, 1997; Hastings & Beck, 2004; Hawkins & Singer, 1989; Pegram, 1989; Wikler, Haack & Intagliata, 1984; Zimmerman & Popynick, 2003) and will not be explored in detail here. However carer support groups may be unsuitable where there are difficulties transporting the child, or arranging for suitable child-care, or for carers who find interpersonal interaction itself aversive. Clinicians seeking to treat parental stress directly may consider individual psychotherapy for carers as an adjunct to behaviour intervention for the child. Formal evaluations of interventions for carers in this context appear infrequently in the literature. Recommended treatment models in the disability literature include Cognitive-Behaviour Therapy (CBT) (Nicoll, Dowling, & Thomas, 2004), Systemic Family Therapy (Rhodes, 2003), Brief Solution-Focussed Therapy (Bratel, Baldry, Dunsel, & Durrant, 2002) and Rational-Emotive Behaviour Therapy (Greaves, 1997). The efficacy of CBT has been empirically established for individuals experiencing symptoms of Generalized Anxiety Disorder (Barlow, Raffa, &

Cohen, 2002) and/or Major Depressive Disorder (Craighead, Hart, Craighead & Ilardi, 2002).

Present Study

The model by Hastings (2002, see figure 9.1) can be amended to indicate two key avenues for intervention via CBT, one cognitive (stressful automatic thoughts) and the other behavioural (personal resources and coping strategies). Figure 9.2 shows an amended version Hastings's model, with CBT intervention points indicated in bold. This amended model also depicts a rationale for providing individual intervention to carers as an indirect means of addressing parenting practices, and thereby the child's challenging behaviour. If carer stress can be reduced through increased personal and social resources, and reduced stressful automatic thoughts, then the interrelated issues of parenting style and child challenging behaviour might also be positively affected. Any resulting improvement in challenging behaviour would, in turn, have an additional positive impact on parental stress.

[Insert Figure 9.2 here]

Method

Design

A case series design was used to observe the effect of an intervention to reduce parental stress on, (a) parental stress; and (b) child challenging behaviour for one male and one female parent. The intervention incorporated Cognitive-Behavioural Therapy strategies into a nine-week program of individual counselling for stress-related behaviours and

cognitions. Parental stress and child challenging behaviour were monitored prior to the commencement of the treatment sessions (collection of pretreatment data), as well as weekly over the nine weeks of sessional treatment (before each session), then finally at six-month follow-up. A brief assessment interview was conducted immediately following the collection of pretreatment data, to ensure that potential risks (e.g., suicidality, substance misuse) were identified and monitored where necessary. Parents were interviewed again after the collection of final follow-up data (six months post treatment), to obtain anecdotal information about their experience of the relationship between stress and parenting style, and changes in the frequency or severity of child challenging behaviour.

Participants

Two parents (one mother, and one unrelated father) participated in the treatment program. Ethical approval for the study was provided by the Macquarie University Ethics Committee (Human research). Participants were recruited via an advertisement placed in the newsletter of the New South Wales Association of Psychologists in Developmental Disabilities and potential participants were asked to contact the researcher by telephone for information about the study. The parents gave written consent to participate in the study and the demographic characteristics of the two cases are provided in Table 9.1. The parents did not know each other and did not meet at any time during the research study. Both parents reported that their children had received behaviour intervention from disability services in the past, but neither was receiving behaviour intervention services at the time of the study.

[Insert Table 9.1 here]

Measures

Each parent was asked to rate their child's challenging behaviour according to the following questions,

1. 'Over the past week, including at night, what percentage of the time did your son/daughter spend doing *any* challenging behaviour, regardless of its intensity?'; and
2. 'Over the past week, on average, whenever the behaviour *was* occurring, what level of intensity would you rate it out of one hundred, where one hundred is the most intense you can imagine it being, and zero is no behaviour at all?'.

Parental stress, depression and anxiety were then measured using the 21-item version of the Depression, Anxiety and Stress Scale (DASS) (Lovibond & Lovibond, 1995).

Development Of Intervention Workbook

To ensure a degree of uniformity for parents, specific psychotherapeutic tasks were gathered into a workbook. Elements for the workbook were selected by examining common elements of generic CBT self-help workbooks (e.g., Barlow & Rapee, 1997; Copeland, 1993; Greenberger & Padesky, 1995), as well as other resources describing the array of CBT techniques available (Leahy, 2003; Giarratano, 2004). From these, techniques were selected that enhanced social and family connections, individual coping strategies, and cognitions, yet required minimal time investment by the parent. The aims of the workbook were to, (1) Assist both parent and researcher by providing a consistent, time-limited agenda for tasks to be carried out during and between therapy

sessions, with supporting information where necessary; and (2) Form a lasting resource for the parent to retain and refer back to after sessions had finished. The elements of the program are summarised in Table 9.2.

[Insert Table 9.2 here]

The workbook comprised of an introduction followed by nine sections, each corresponding to a weekly one-hour session focusing on a different CBT element or coping strategy. The sections contained self-administered exercises, narrative explanations of concepts (such as principles of controlled breathing), and record forms (such as thought monitoring forms). Each component of the workbook was labeled to indicate if it was a collaborative exercise, or to be carried out by the parent between sessions. All notes and entries were made by the parent or therapist directly into the workbook, which formed a single record of all work done during and between sessions, and which could be reviewed if necessary by the parent during times of future need.

Results

Participation In Treatment

Both parents completed all tasks and were able to demonstrate proficiency in the skills involved in the treatment program. Both parents completed the nine program elements over a ten week period. In each case, intervention was interrupted approximately mid-way through the nine weeks, resulting in a mid-program gap of one week. Due to time constraints, follow-up data was collected six months after completion of intervention for parent A, and four months after completion for parent B.

Feedback From Parents During Follow-up Interview.

Both parents reported during the follow-up interviews that they were continuing to refer to the workbook, and continuing to use more than one, but not all, of the strategies in it. Both parents felt the intervention was beneficial for them, but only parent A reported a decrease in her child's challenging behaviour, while parent B reported an overall increase in behaviour severity. Both parents commented that they found behaviour incidents less stressful, although parent B reported ongoing concern about the challenging behaviour overall and the impact of the behaviour on his family.

Quantitative Results

[Insert Table 9.3 here]

All of the raw scores for both parents are presented in Table 9.3. Challenging behaviour 'product' scores were generated by multiplying frequency rating by severity rating. Between-parent Pearson correlations of r = 0.675, r = -0.690, and r = 0.563 were obtained for weekly DASS (total) score, weekly challenging behaviour frequency rating and weekly challenging behaviour severity rating respectively. A Pearson correlation of r=0.191 was obtained for challenging behaviour frequency and challenging behaviour severity using data from both parents. Pearson correlations were calculated for mean parent ratings of child challenging behaviour and mean DASS scores. The coefficients thus generated are presented in Table 9.4.

[Insert Table 9.4 here]

Observed Effects Of Intervention

Changes in parent stress (DASS total) and challenging behaviour (product) are summarized in Figure 9.3. This figure depicts mean scores for the measures of parent stress and challenging behaviour over time.

[Insert Figure 9.3 here]

Discussion

Challenging Behaviour Ratings

The low correlation between parent ratings of challenging behaviour frequency and severity indicated that the parents responded to these two questions in an orthogonal way. The moderate correlation between DASS scores and behaviour severity may have reflected the subjective nature of this behaviour rating, while the near-zero correlation between DASS scores and behaviour frequency may indicate that frequency ratings provide more objective information about the status of challenging behaviour. This has implications for clinicians who are often forced to rely solely on parent report when monitoring challenging behaviour over time. With careful question wording, orthogonal estimates of frequency and severity can be obtained, with frequency rating providing a more subjective indication of the parent's experience of the behaviour, and severity rating providing a more objective indication of the challenging behaviour.

Interpretability Of Results

Both parents were highly motivated to participate in treatment, despite both also indicating that they felt their children were in greater need of intervention. The ‘n=2’ design of this study precludes all but the most tentative inferences being made about the wider population. Nevertheless, some of the results obtained bear interpretation at a broader level. In particular, the moderate correlations between child challenging behaviour severity ratings and parental DASS scores align data from the current study with data from other studies that confirm this link thus allowing the results to be interpreted somewhat more broadly.

Parent Stress And Child Challenging Behaviour

Two key trends may be observed in the results, best reflected in Figure 9.3. Firstly, overall parent stress appears to have steadily reduced over the course of the intervention and remained low at follow-up. Secondly, although child challenging behaviour fluctuated during the intervention in a way that does not suggest any particular pattern (for example, the behaviour did not reduce over time), there appears to have been a progressive dissociation between the parent’s stress level and their child’s challenging behaviour. During early sessions, stress and behaviour appeared to have moved in unison, while this link appeared to have diminished in later sessions and at follow-up. This trend was also reflected in the comments of both parents that they were experiencing less subjective distress during behaviour incidents as a result of participation in treatment. Parent B commented during the follow-up interview that ‘even if the behaviour got worse, it does not affect me as much as it used to’. Even where the child challenging behaviour remained elevated, the reduced degree to which

parents' emotional states were 'at the mercy' of the child's behaviour was itself an important treatment outcome.

Conclusion

The relationship between child challenging behaviour, parent stress, and parenting style proposed by Hastings (2002) continues to be an important and useful model for clinicians working with families. Further research is needed to verify the causal link between parental stress and child challenging behaviour, and the present study provides a model for such research to be carried out with a larger sample. Regardless of the precise mechanism of the interrelationship between parental stress and child challenging behaviour, the association between these two phenomena means clinicians may target either one of them, in order to improve both. Where the clinician is struggling to address the behaviour, they may opt instead to target parental stress, in the knowledge that this may be an indirect avenue to behavioural intervention. If challenging behaviour and parental stress are reciprocally causal, then it is important that clinical intervention for the parent is given at least equal attention as the behaviours of the child.

Acknowledgments

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Table 9.1

Characteristics Of Cases

Parent	**A**	**B**
Sex	Female	Male
Employment Status	Not employed	Full-time
Spouse Employment Status	Full-time	Not employed
Residential Area	Medium-density suburban North-west Sydney	Medium-density suburban North-west Sydney
Age of child	15	11
Child's reported level of Intellectual Disability	Severe	Severe
Reported behaviour(s) of concern	Verbal and physical aggression to self and others	Verbal and physical aggression to self and others

Table 9.2

Elements Of Treatment Program

Week	Session Topic
1	Introduction to the workbook and development of joint definition of challenging behaviour
2	Development of joint understanding of interrelatedness of CB, parent stress, and parenting style.
3	Motivational interviewing and Goal Setting.
4	Planning for Enhancing support network, and pleasant activity scheduling.
5	Relaxation via diaphragmatic breathing, progressive muscle relaxation, and visualisation.
6	Feelings identification.
7	Identifying automatic thoughts.
8	Challenging automatic thoughts.
9	Review and relapse prevention.

Table 9.3

Raw Scores Obtained For Both Parents On DASS And Challenging Behaviour Ratings

		Week									
Measure	**Parent**	**1 (pre-treatment)**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**follow-up**
DASS (depression)	A	17	16	7	7	0	0	0	0	1	4
	B	10	16	9	7	7	9	8	11	8	7
DASS (anxiety)	A	9	13	6	4	1	0	0	1	1	6
	B	5	11	6	3	3	4	7	5	4	6
DASS (Stress)	A	15	17	10	9	1	1	1	3	3	7
	B	10	13	9	10	9	10	9	10	8	9
DASS (Total)	A	41	46	23	20	2	1	1	4	5	17
	B	25	40	24	20	19	23	24	26	20	22
Challenging Behaviour (frequency)	A	70%	80%	90%	70%	45%	45%	45%	60%	60%	40%
	B	30%	40%	40%	50%	55%	58%	60%	55%	40%	50%
Challenging Behaviour (severity)	A	80%	60%	35%	35%	8%	8%	8%	8%	40%	45%

	B	60%	50%	50%	35%	50%	63%	70%	55%	55%	60%
Challenging Behaviour (product)	A	0.56	0.48	0.32	0.25	0.03	0.03	0.03	0.05	0.24	0.18
	B	0.18	0.20	0.20	0.18	0.28	0.37	0.42	0.30	0.22	0.30

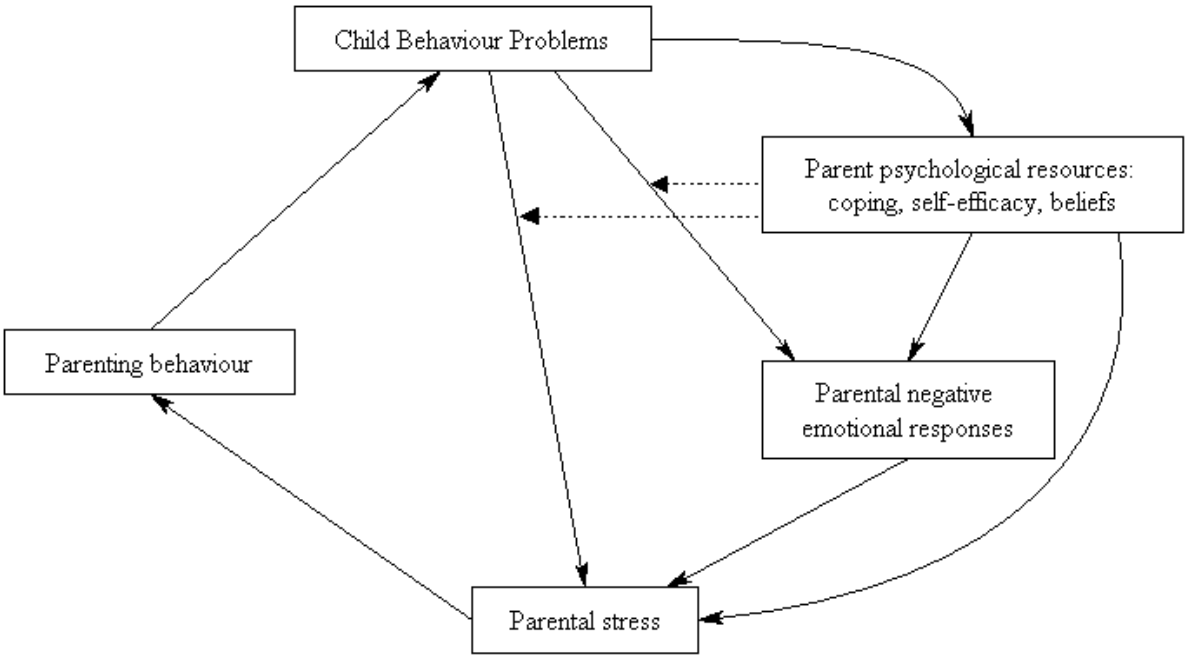
Table 9.4

Pearson Correlation Matrix Of Stress And Behaviour Level Measures.

	DASS scores			
	Total	Depression	Anxiety	Stress
Challenging Behaviour				
Frequency	0.365	0.351	0.308	0.408
Severity	-0.076	0.009	-0.005	0.174
Product	0.197	0.285	0.183	0.107

Figure 9.1

Model Illustrating Key Variables Affecting The Relationship Between Child Behaviour Problems And Parental Stress



Source. Hastings (2002). Copyright 2002 ASSID. Reprinted with permission (*pending*).

Figure 9.2

Re-Conceptualized Model Of Relationships Between Child Behaviour Problems And Parental Stress (Potential New Intervention Points Are Identified In Bold)

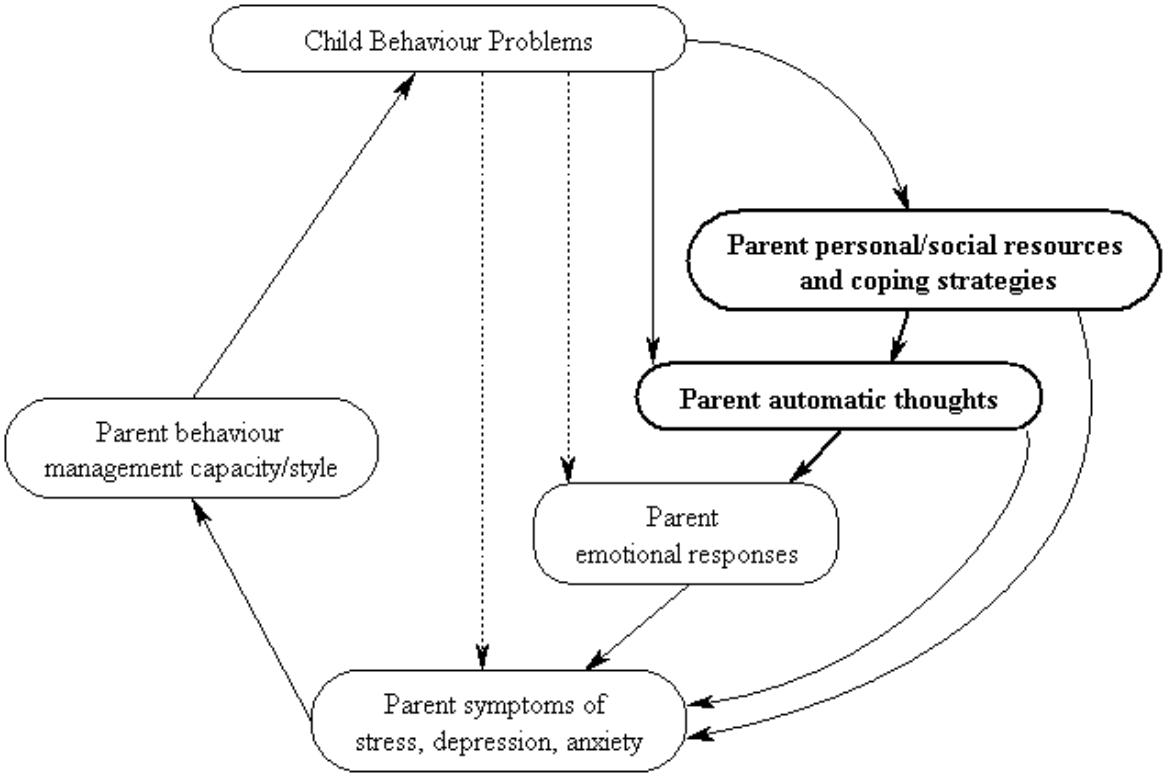


Figure 9.3

Trends On Mean DASS Total Scores And Challenging Behaviour Score Products During And After Intervention. While challenging behaviour appeared to fluctuate, DASS scores decreased, becoming more independent of challenging behaviour level.