

Change in Mental Health Status of Young Children Participating in a Respite Service

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Abstract

Objective: The objective of this study was to determine the extent of changes in mental health status of children in a respite service as little has been reported on this aspect of respite care. **Method:** All families enrolled in a new centre-based respite program in a moderately large urban center in Canada were invited to participate. The child's primary caregiver completed the Strengths and Difficulties Questionnaire (SDQ) at baseline, mid-point and endpoint, as did respite staff. A comparison group of primary caregivers seeking respite care also completed the same ratings at baseline and at one-follow-up point. **Results:** The children's primary caregivers perceived high levels of mental health difficulties in their children at baseline; significantly more than respite providers. No significant changes were found between SDQ baseline and endpoint values for either primary caregivers or respite workers. The amount of change between baseline and midpoint was no different for the intervention and comparison group. **Conclusions:** No evidence of a positive impact on child mental health status by the new respite program as measured by the SDQ was detected. Specific evidence-based child mental health interventions may need to be paired with respite care to improve child mental health outcomes.

Key words: respite care, child, mental health, evaluation

Résumé

Objectif: évaluer les changements de statut mental d'enfants qui se trouvent dans un service de relève, étant donné qu'il existe peu d'études sur ce sujet. **Méthodologie:** toutes les familles inscrites à un nouveau programme de relève centralisé dans une ville canadienne de moyenne importance ont participé à cette étude. Le soignant principal de l'enfant et le personnel de relève ont répondu au SDQ (Strength and Difficulties Questionnaire - questionnaire sur les forces et les difficultés) en début, milieu et fin d'étude. Un groupe témoin de soignants principaux à la recherche d'un service de relève a également rempli ce questionnaire en début et en cours d'étude. **Résultats:** les soignants principaux ont constaté, beaucoup plus que les intervenants des services de relève, que les problèmes de santé mentale des enfants étaient nettement plus marqués en début d'étude. On ne constate aucune différence significative entre les notes attribuées au SDQ par les soignants principaux ou par les intervenants du service de relève, en début et en fin d'étude. L'écart entre les résultats de début et de milieu d'étude était identique dans le groupe d'intervention et dans le groupe témoin. **Conclusion:** le SDQ n'a pas permis de confirmer l'impact positif du nouveau programme de relève sur le statut mental des enfants. Des interventions concrètes précises sur la santé mentale des enfants devront être associées aux soins prodigués par les services de relève afin d'améliorer les résultats.

Mots clés: service de relève, santé mentale, enfants, évaluation

Introduction

Respite care refers to the temporary care of individuals with disabilities (e.g., developmental delay, cognitive decline, emotional-behavioural disturbances and physical disabilities) for the purpose of providing relief to the family or primary caregiver (McNally, Ben-Shlomo, & Newman, 2000). Respite also seeks to support and stabilize the family unit

(McNally et al., 2000) and improve the quality of life of those involved (Neufeld, Query, & Drummon, 2001). Respite care is a frequently considered service for families struggling with raising children, particularly those with emotional, behavioural and/or developmental problems. However, these services are rarely evaluated, particularly with consideration of child mental health status.

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Although a focus on the impact of respite care on caregiver stress is an important domain, there should also be a consideration of the impact of respite care on child mental health and child function. Attention to child function is important in and of itself, as it predicts adjustment in later life (Berk, 2008). Additionally, child difficulties may be a source of familial and parental stress (Doig et al., 2009). A reduction in child difficulties may contribute to a decrease in stress and an improvement in family function, which is an important aim of respite care. Furthermore, concerns have been raised about potential adverse impacts of respite care, such as the strain on the child-caregiver bond upon separation (Chan & Sigafoos, 2001), and homesickness as experienced by the child (Radcliffe, 2007). Thus, incorporating a focus specifically on child status within evaluations of respite services is essential.

Unfortunately, the impact of respite services on children with emotional-behavioural problems has received little scrutiny (Bruns, 2000). An exception includes an exploratory investigation of the impact of respite care on children with autistic spectrum disorders (ASDs) (Preece, 2002). In the latter study, the author utilized qualitative methods (“structured consultation” with children, structured interviews with parents, teachers and respite providers pre- and post-consultation, and synthesis of researcher’s field notes) to capture the children’s perspectives and experiences in short term residential care with three families. It was concluded that consistency in respite providers’ approach to care and staff-to-child ratios, training, and skill were important variables that probably impacted the child’s experience. No studies were found that used quantitative measures to assess change in child mental health status following participation in a respite intervention. The current study aimed to determine: (i) the mental health status of children enrolled in a new respite service, (ii) the changes in children’s mental health status over time, and (iii) whether the amount of change was greater than a comparison group not enrolled in the new respite service.

Methods

Intervention and Setting

The intervention consisted of a centre-based respite program developed by two service provider agencies in a Canadian urban center with a population of approximately 1 million. Children attended the centre-based program for approximately six hours per week (Tuesday and Thursday evenings for three hours each or Saturday for six hours) for ten months (September to June). Children attended a mean of 85% (SD 17%) of respite sessions. Children in the program were designated to a regular small group (i.e., consistent groups of children were assigned to the same respite workers), with a child to staff ratio of 3:1. This respite program provided traditional

relief (relieving the primary caregiver of their duties) while also providing semi-structured activities for the children (including various recreational, social and play activities) which were supervised by trained and experienced staff. The program was housed in a facility designed for special needs children which had a rich array of toys and recreational centres for various developmental ages. The children rotated, within their group, to a variety of play and activity stations during each respite session. The program social worker and respite staff were available to meet with caregivers, though caregivers were not required to attend and transportation was available to ensure the caregiver had a break during the respite period.

Funders of the new respite service required an evaluation to be conducted by an independent research group. A mixed method research evaluation was conducted which included *a priori* research questions including hypothesized positive changes in child mental health status as a function of participating in the new respite service. Details on the larger evaluation are reported elsewhere (McLennan, Urichuk, Farrelly, and Hutcheon, 2009).

Sample

All families enrolling in the respite program in the fall of 2006 and fall of 2007 were invited to participate in the associated evaluation. The program was advertised in a number of community newspapers, newsletters of special interest groups and brochures explaining the program, and distributed to many agencies and clinics. Families were referred by various agencies or self-referred. Child age eligibility was restricted to three to eight years of age. In addition, preferential access was given to children prenatally exposed to alcohol and/or with fetal alcohol spectrum disorders (FASD), given the special interest of the funders. However, children with no known prenatal alcohol exposure were also included.

Of 62 families with 85 children participating in the respite service, 45 families (72.6%) with 62 children (72.9%) agreed to participate in the evaluation. To avoid potential bias contributed by including more than one child per family, only one child per family, randomly chosen, was included in the analysis for this report. Furthermore, complete data on the key mental health measures was required at baseline and endpoint. This reduced the final sample size to 31 families with 31 children.

Families with children with similar characteristics who were seeking urgent respite services through a different local respite provider were invited to participate in the study as a comparison group. The respite care provided in the latter case was short term and not pre-scheduled. Eleven families with 11 children in the comparison group had complete information at baseline and follow-up, again using the one child per

family restriction. The follow-up point for the comparison group, approximately four months post baseline, corresponds to the midpoint for the intervention group. Information at midpoint was only available for 27 of the 31 families used in the endpoint analysis from the new respite program described earlier. Ten month follow-up data for the comparison group were not reported due to small sample size from loss of sample over time via attrition.

Measures

The Strengths and Difficulties Questionnaire (SDQ) served as the measure of child mental health. The SDQ has parallel versions for parents (primary caregivers) and teachers (used by respite workers in this study). The SDQ is composed of five subscales (Emotional Symptoms, Conduct Problems, Hyperactivity-Inattention, Peer Problems, and Prosocial Behaviour), each of which are comprised of five items or attributes scored on a three point scale. All subscales, except Prosocial Behaviour, are summed to generate a Total Difficulties Score (Goodman, 2001). Recommended cutpoints indicating scores in the abnormal ranges were used for each of the subscales (YouthinMind, 2009a). Good psychometric properties have previously been reported (Goodman & Scott, 1999; Klasen, Woerner, & Wolke, 2000; Goodman, 2001; Bourdon, Goodman, Rae, Simpson, & Koretz, 2005). The instrument has been found to be both useful using the categorical cut points and as a continuous measure (Goodman & Goodman, 2009). Interrater correlation (parent-teacher) for total difficulties was found to be 0.46 (Pearson's correlation) in a large British sample (Goodman, 2001).

For the intervention group, the SDQ was completed at baseline (program entry), midpoint (approximately four months later) and endpoint (at end of program, approximately ten months post baseline) by the primary caregiver and respite worker. Respite workers completed the baseline measure approximately four weeks after the child entered into the program in order to have some basis for scoring. For the comparison group, primary caregivers completed the SDQ at baseline and approximately four months later (approximating the mid-point for the intervention group). Although the participating caregivers knew the SDQ and other instruments were being collected as part of the larger research evaluation project, they were not aware of the specific analysis of determining change in this measure across time and in comparison with another group. Research staff members were available to caregivers who may have had questions about completing the SDQ, although it is quite self explanatory.

Analysis

For the intervention group, statistical difference in the number of children scored in the abnormal range by primary caregivers versus respite workers at baseline were computed

using the Sign test. Paired t-tests were used to assess the changes in the continuous scores from baseline to endpoint for both the primary caregivers and respite workers. Independent t-tests were used to compare the amount of change in continuous values between baseline and mid-point for the intervention versus comparison group. A calculation to estimate the "added value" of the intervention was applied to the change data for the primary caregiver SDQ data; an approach which aims to adjust for anticipated regression towards the mean and a certain level of spontaneous improvement (YouthinMind, 2009b; Ford, Bywater, Goodman, & Goodman, 2009).

Ethics

The study was approved by the ethics committee of the University of Calgary/Calgary Health Region and the University of Alberta/Capital Health Region. Participating primary caregivers and respite workers completed written informed consent forms. Children were not asked for assent given their young age; in addition the children provided no direct research data. Participants were assigned research identification numbers to prevent specific identification.

Results

Characteristics of the participants are summarized in Table 1. The intervention group selected for analysis did not differ from those excluded. More of the comparison group were biological parents, and this difference was statistically significant.

The majority of the primary caregivers in the intervention group rated their children in the abnormal range for Conduct Problems, Hyperactivity-Inattention, and Peer Problems at baseline (Table 2). The respite providers rated a smaller percentage of these children at the abnormal level. There were no significant reductions in any of the subscales scores from baseline to endpoint for either primary caregiver or respite provider ratings. Age of the child was not significantly correlated (Person's) to change in SDQ total difficulties score ($r=0.048$, NS).

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Primary caregivers of the comparison group rated fewer children in the abnormal range compared with the intervention group at baseline, although this was only statistically

Table 1. Baseline characteristics of different study participants

Characteristics	Intervention group for analysis (n = 31)		Intervention group excluded (n = 31)		Comparison group (n = 11)
	% (n)		% (n)		% (n)
Child gender (male)	58.1 (18)		64.5 (20)		55.6 (5) ²
Reported prenatal alcohol exposure					
"Definitely No"	35.5 (11)		32.3 (10)		70.0 (7) ¹
"Probably No"	0.0 (0)		0.0 (0)		0.0 (0)
"Probably Yes"	3.2 (1)		0.0 (0)		10.0 (1)
"Definitely Yes"	54.8 (17)		67.7 (21)		20.0 (2)
"Don't Know"	6.5 (2)		0.0 (0)		0.0 (0)
Child ethnicity					
Caucasian	38.7 (12)		34.5 (10) ²		30.0 (3) ²
North American Indian	29.0 (9)		27.6 (8)		20.0 (2)
Metis	16.1 (5)		13.8 (4)		0.0 (0)
Mixed	9.7 (3)		13.8 (4)		30.0 (3)
Aboriginal (not specified)	3.2 (1)		6.9 (2)		10.0 (1)
Black	3.2 (1)		3.4 (1)		0.0 (0)
Respondent's relationship to child					
Biological mother	30.0 (9) ¹		31.0 (9)		100.00 (10) ¹
Biological father	6.7(2)		3.4 (1)		
Foster mother	26.7(8)		44.8 (13)		
Adoptive mother	16.7(5)		3.4 (1)		
Adoptive father	3.3 (1)		3.4 (1)		
Other female	16.7(5)		13.8 (4)		
	Mean (S.D.)		Mean (S.D.)		Mean (S.D.)
Child age (years)	5.3 (1.5)		5.4 (1.9)		5.4 (1.7)
Number of people in household	4.7 (1.7)		6.0 (1.9) ²		4.3 (1.0)
Total difficulties score on SDQ at baseline	Primary caregiver	Respite provider	Primary caregiver	Respite provider	Primary caregiver
	23.1 (6.5)	14.4 (9.0)	23.7(5.8) ⁴	11.2(8.3) ⁶	18.0 (6.9)

¹Missing 1 case, ² Missing 2 cases, ⁴Missing 4 cases, ⁶Missing 6 cases

significant for the Hyperactivity-Inattention subscale (Table 3). The amount of change in subscale scores from baseline to midpoint was not statistically different between the two groups, and there was no significant improvement in scores over this time period for either group.

Discussion

Although the respite service under investigation in this study had a number of the components Preece (2002) described as being important for improving child outcomes (i.e., consistency in respite providers' approach to care, staff-to-child ratios, training, and skill), no evidence of improvement was

detected in child mental health status by the end of the intervention by either the primary caregiver or respite staff. This occurred despite the relatively intensive service as reflected in the frequency and duration of the program. A number of reasons may have contributed to this finding. Of note, while there was no evidence of improvement, there was also no evidence of harm.

There is the possibility that there were important gains made that were not captured by the primary child mental health measure. Only a single measure of child mental health was used in this study, i.e., the Strengths and Difficulties Questionnaire (SDQ). No single measure is able to capture all

Table 2. Pattern of SDQ scores at baseline and endpoint as perceived by caregiver and respite provider^{a,b}

Variables	Parent/Caregiver (n = 31)				Respite provider (n = 31)			
	Abnormal range % (n)		Continuous scores Mean (S.D.)		Abnormal range % (n)		Continuous scores Mean (S.D.)	
	Baseline†	Endpoint	Baseline†	Endpoint	Baseline†	Endpoint	Baseline†	Endpoint
Emotional Subscale	48.4 (15)*	44.8 (13) ²	4.8 (2.8)	4.0 (2.6)	23.3 (7) ¹	16.1 (5)	2.9 (2.7)	2.7 (3.1)
Conduct Subscale	80.6 (25)*	74.2 (23)	5.8 (2.5)	5.2 (2.7)	36.7 (11) ¹	41.9 (13)	2.6 (2.4)	3.2 (2.2)
Hyperactivity-Inattention Subscale	80.0 (24) ¹	71.4 (20) ³	8.2 (2.0)	7.5 (2.4)	40.0 (12) ¹	41.9 (13)	5.9 (3.6)	5.9 (3.3)
Peer Problems Subscale	61.3 (19)*	75.0 (21) ¹	4.3 (2.0)	4.3 (2.4)	26.7 (8) ¹	32.3 (10)	3.0 (2.4)	2.7 (2.5)
Total difficulties score	83.9 (26)**	80.0 (24) ¹	23.1 (6.5)	21.0 (7.3)	46.7 (14) ¹	41.9 (13)	14.4 (9.0)	14.4 (8.0)
Pro-social (deficit) Scale	16.1 (5)	33.3 (9)	6.3 (2.3)	5.9 (2.7)	23.3 (7) ¹	26.7 (8) ¹	5.8 (2.6)	6.2 (2.5)

^a Analysis was restricted to all those with baseline and endpoint data

^b No significant differences between baseline and endpoint found using paired t-tests on continuous scores for either the primary caregiver or respite provider ratings

† Starred values in this column represent the extent of statistical differences between the primary caregiver baseline ratings of abnormality and that of the respite providers using the sign test (*p<0.05, **p<0.01)

¹ Missing 1 case, ²Missing 2 cases, ³Missing 3 cases

Table 3. Comparison of caregiver SDQ values at baseline and midpoint for the intervention and comparison groups^a

Variables	Intervention group (n = 27)		Comparison group (n = 11)		Intervention group (n = 27)	Comparison group (n = 11)
	% Abnormal range				Change in continuous scores	
	Baseline† % (n)	Midpoint % (n)	Baseline† % (n)	Midpoint % (n)	Mean (S.D.)	
Emotional Subscale	48.4 (15)	37.0 (10)	45.5 (5)	36.4 (4)	-1.26 (2.38)	-0.45 (3.01)
Conduct Subscale	80.6 (25)	77.8 (21)	54.5 (6)	36.4 (4)	-1.00 (2.48)	-1.45 (1.81)
Hyperactivity-Inattention Subscale	80.0 (24)*	63.0 (17)	45.5 (5)	45.5 (5)	-0.93 (2.37)	0.27 (2.20)
Peer Problems Subscale	61.3 (19)	63.0 (17)	45.5 (5)	27.3 (3)	-0.44 (2.30)	-0.09 (2.43)
Total difficulties score	83.9 (26)	70.4 (19)	63.3 (7)	54.5 (6)	-3.63 (6.71)	-1.73 (6.86)
Pro-social (deficit) Scale	16.1 (5)	7.4 (2)	9.1 (1)	0.0 (0)	0.52 (1.90)	0.64 (1.12)

^a mean change scores did not significantly differ between intervention and comparison groups (using independent t-tests of continuous data).

† Starred values in this column represent the extent of statistical differences between percentages in the abnormal range for the intervention group and comparison group at baseline using chi-square analysis (*p<0.05, **p<0.01).

potential mental health gains. However, the SDQ has strong psychometric properties and, when used as an outcome measure in other studies, has been able to detect positive outcomes (Mathai, Anderson, & Bourne, 2003). Nevertheless, a number of families reported several positive aspects of the program (e.g., provision of a break, opportunity for children to socialize) as reported on the caregiver feedback component and as emerged from the qualitative inquiry component of the larger study (McLennan, Urichuk, Farrelly, & Hutcheon, 2009).

However, if no significant child mental health gains were actually made as a function of the new respite service, there are a number of potential contributors. One is that the intervention was not specifically aimed at or resourced to make direct shifts in key child mental health difficulties. For example, symptoms of attention-deficit/hyperactivity disorder (ADHD) were some of the most frequently reported child difficulties. Interventions with the most evidence for effectiveness for ADHD are employment of behavioural modification strategies and/or use of medication (Pelham & Fabiano, 2008; Pliszka, 2007). Neither of these were core elements of the respite service, though potentially they could have been accessed outside of the respite service. This raises the question as to whether it is reasonable to expect respite services alone to result in child mental health improvements when the service is predominately aimed at alleviating caregiver stress.

Related to this prior point, a second possibility is that the respite service was not sufficient to alleviate parental stress which may have impeded potential gains children may have made if parent stress was reduced. Little reduction in parent stress was detected in this population as measured by the Parent Stress Index-Short Form (McLennan, Farrelly, Doig, & Urichuk, 2009; Abidin, 1995). Suggested reasons for failing to make significant reductions in stress may have been a function of not providing sufficient sibling care (hence the parent did not always receive a break from all child care responsibilities) and/or the breaks were not long enough to make significant gains, or other factors in the caregivers' lives were not improved. Furthermore, one could argue the failure to effect improvements in child mental health status contributed to the failure to reduce caregiver stress.

Noteworthy is that the primary caregivers rated their children as having significantly greater difficulties than the respite workers. The lack of agreement is not surprising as differences in perception of child behaviour by different informants have been frequently reported (e.g., parent, teacher, self-reports) (McGee, Silva, & Williams, 1983). These differences may be at least in part a function of the contextual dependency of the behaviour and/or the perceptions of problematic behaviour differing between the two raters (McGee et

al., 1983). The extent to which these factors contributed to the discrepancy in this group is unknown.

Limitations

A key limitation to this study is the relatively small sample size. This limits the ability to detect small to medium effects. This was particularly a problem for the comparison group which proved to be quite difficult to recruit. This is perhaps not surprising, as participation in a research study would presumably be a low priority for families who are in the midst of seeking respite support. However, this small comparison group does provide some preliminary evidence against a potential alternative hypothesis that no pre-post change in the intervention group was actually an encouraging finding as it may represent the prevention of deterioration in child mental health status in respite seekers who do not receive this particularly intensive service.

A second limitation is the representativeness of the participants. This was a new respite service and there were multiple referral points with a preference to include children with prenatal alcohol exposure and/or FASD. The extent to which the resulting population reflects typical respite seekers is unknown. Third, though there was a small comparison population, there was neither random assignment nor an experimental design, which would have more rigorously evaluated the effect of the respite service.

Future Recommendations

There is clearly more need for evaluation of the impact of different respite services for a variety of outcomes, with particular attention to child mental health outcomes. One particular avenue that should be pursued and evaluated is to what extent linking respite services with evidence-based interventions for improving child mental health may result in further improvement. One component that this respite service is considering is the addition of a parenting program. While there is some concern that this may take time away from the respite break, there is the potential for peer-support and an avenue for implementation of evidence-based behavioural modification strategies in the home where needed.

The inclusion of psychometrically sound child mental health measures should be incorporated in future respite evaluation projects. Inclusion of the SDQ would facilitate comparison with this and other studies using this instrument. However, simultaneous inclusion of other instruments may help to determine whether other positive child mental health impacts might be missed by the SDQ. This may include longer and more comprehensive instruments such as the Achenbach Child Behavioral Checklist and Teacher Report Forms (Achenbach, 1991).

Acknowledgements / Conflicts of Interest

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