Stress and Relief: Parents Attending a Respite Program

John D. McLennan MD, PhD1; Jenna Doig MD2; Carmen Rasmussen PhD3; Emily Hutcheon BHSc1; Liana Urichuk PhD3,4

Abstract

Objective: The objectives of this study were to examine changes in stress among parents of children with special needs in a respite service and consider parental experience of the service. Methods: Families who were enrolled in a ten-month centre-based respite program were invited to participate in the evaluation. Change in parent stress, indexed by the Parent Stress Index-Short Form (PSI-SF), was determined. These results were compared with findings from exploratory qualitative interviews with a subset of parents and a small comparison group who also completed the PSI-SF. Results: At baseline, 69% of parents (n=45) had high total stress scores on the PSI-SF. No significant improvements were detected on parent stress over time or differences from improvements in the comparison group. In contrast, the subgroup of parents (n=10) who participated in the qualitative interviews described substantial benefits from the respite program including a sense of relief and having time for other activities. Conclusions: It is proposed that the respite program may have provided a temporary break to parents thereby bestowing a sense of relief, but was not adequate to impact on more chronic stress patterns, suggesting that these are related but separate constructs and experiences.

Key words: respite care, stress, parent, mixed methods

Introduction

While stress is a common parental experience, high parental stress has been related to a number of concerns including increased use of undesirable parenting strategies (Rodgers, 1993), internalizing (Bakoula, Kolaitis, Veltsista, Gika, & Chrousos, 2009) and externalizing problems (Bagner et al., 2009), as well as lower social competence in children (Anthony et al., 2005). Periods of high stress may be more common for those parents caring for children with...
mental and/or developmental problems or at risk for such (Evans, Sibley, & Serpell, 2009; Paley, O’Connor, Frankel, & Marquardt, 2006; Norizan & Shamsuddin, 2010; Secco, Askin, & Yu, 2006; Tervo, 2010; Wulffhaet, Scholte, & Van Berckelaer-Onnes, 2010).

Strategies aimed at reducing parent stress may be beneficial to children and their parents. Respite care, a temporary break provided to caregivers, is one class of interventions which may help reduce parent stress. Prioritizing families with children with mental and/or developmental problems for respite care may be appropriate given their typical higher stress levels and greater needs. However, the evidence-base for the effectiveness of different types of respite care is thin, impeding efforts aimed at evidence-informed service improvements.

From a narrative review of studies of respite care for families with a child with developmental disabilities completed a decade ago, it was concluded that there was some evidence for a reduction of parental stress with respite services but various methodological limitations were noted in the few studies identified (Chan & Sigafoos, 2001). There also needs to be substantial caution in making blanket statements about the effectiveness of a service that can take such varied forms (e.g., home-based versus centre-based), intensities, and durations. A more recent review identified 15 studies and identified a pattern of parent stress reduction with respite services; however, the author noted the continued limited research database and methodological limitations to the studies identified with only two of the studies employing even a quasi-experimental design (Strunk, 2010). One of the quasi-experimental designs contrasted a respite care service consisting of an inpatient admission for a mean of 8.8 (S.D. 3.1) days without explicit evaluation and treatment components (n=14) and contrasted this with an inpatient hospitalization of a mean of 63.9 (S.D. 43.6) days with evaluation and treatment components (n=18) (Aniol, Mullins, Page, Boyd, & Chaney, 2004). While direct analysis of the change of the parent stress measure was not reported, analysis of the data available in a table in this paper found no evidence of significant reduction in either group. In contrast, the other quasi-experimental study did find a significant decrease in parent stress (Mullins, Aniol, Boyd, Page, & Chaney, 2002). This similar study by the same study group compared an inpatient respite stay of a mean of 9.3 (S.D. 8.1) days (n=39) to an inpatient hospital stay of a mean of 48.4 (S.D. 27.2) days (n=41) (Mullins et al., 2002). Parent stress was found to significantly drop from pre-to post-intervention for both groups but returned to pre-intervention levels at the six month follow-up (Mullins et al., 2002). Given this limited database, further evaluation of respite services for families with children with special needs is required.

Objectives

The objective of this study was to examine stress of parents who attended a centre-based respite program for children with special needs using a mixed methods approach. The research questions were:

1. What are the changes in stress levels over time for parents who are participating in a new centre-based respite program?
2. How do these changes differ from a comparison group not exposed to this new centre-based respite program?
3. How do parents describe their experience of this new centre-based respite program and how do these compare with quantitative measures of stress?

Methods

General: This study included a pre-post quantitative assessment of parent stress in a naturalistic follow-up of participants in a new respite program, and a comparison group not in this respite program, as well as a qualitative exploratory component with participants in the new respite program. Throughout this paper, the participating child’s guardian is referred to as “parent,” however, as detailed in Table 1, this includes guardians other than biological mothers and fathers. In all cases, the “parent” was providing a central parenting role for the child at the time of the study.

Sample: Sample 1 (“Intervention Group”) is composed of parents of young children (aged three to eight) participating in a new centre-based respite program. All parents enrolling within a two-year period were eligible to participate in the associated evaluation. In total, 85 children started the respite program over the two years. Parents of 62 children (72.9% of total) agreed to participate in the evaluation study. Twelve families had more than one child in the program (eight families with two children each, and four families with three children each). To avoid more than one rating per family, one child was randomly selected for each family with more than one child participating. This reduced the sample size to 46 at baseline. The participating parent completed the core parent stress measure (described below) at baseline (n=45), interim-follow-up (three to four months after program start) (n=35), end-point of the program (approximately ten months) (n=29) and at follow-up (approximately six months later) (n=21). Sample size at each subsequent point decreases due to lack of completion of ratings at later points. For analysis contrasting the intervention and comparison group, sample was restricted to those with both baseline and interim data points (n=35).

Children/families entered the program upon referral from various community agencies based on agencies’ perceptions of a need for respite or belief that the child or family would benefit from such. Funders of the respite service wanted preferential access to children who had fetal alcohol

spectrum disorder (FASD) or at-risk for such given reported prenatal alcohol exposure. Therefore agencies serving this population were notified and had first access to the service. However, space was also available for children with no reported previous alcohol exposure. These latter children were principally referred from a call centre receiving respite service requests. In addition to the age requirement, these children also had to have demonstrated some mental health difficulties, which were indexed by scoring in the abnormally high range on the parent-report Strengths and Difficulties Questionnaire (Goodman, 2001; YouthinMind, 2009). Given incomplete access to medical records, it was not possible to determine those children who had an FASD diagnosis, however a screening question was asked of the current parent as to alcohol exposure in utero and 56.3% indicated definite prenatal alcohol exposure (although no further information was gathered).

A subgroup of Sample 1 (“Qualitative Inquiry Group”), participated in qualitative exploratory interviews. Research staff approached several parents in the respite program who had participated in the quantitative component of the study to participate in a qualitative interview. They were approached towards the end of their participation in the respite program. There was an explicit aim to obtain different types of parents. In total ten parents were recruited: six foster mothers; two biological mothers; and, two grandmothers. Four of the parents had two children attending the program; all others had one. Eight of the ten had parent stress data at baseline and the interim time point.

Sample 2 (“Comparison Group”) is composed of parents of children with similar characteristics to those in Sample 1, but who sought respite care through a different service provider in the same city (the “comparison group”). This turned out to be a particularly difficult population to recruit and retain in the study, although not surprising given most would have more pressing priorities than participation in a research project. Only 11 families with 11 children were available for this analysis (we used the same restriction of including only one child per family as in Sample 1). While not able to enter the new centre-based respite program because it was full, the call centre for respite services offered their regularly available services which typically included short-term crisis respite services.

Intervention: The centre-based respite program was a new service located in a major urban centre in Canada. Children were eligible to attend six hours/week of respite care for ten months (Tuesday/Thursday evenings or Saturdays). The children engaged in a variety of activities each session including activities centres, physical activity, and snack time. All front-line staff were experienced working with children and families. Of note, this was not a research intervention, but a community developed respite program with an associated research evaluation.

Measures: The Parent Stress Index-Short Form (PSI-SF) was the core quantitative measure employed to measure parental stress. This is a 36-item standardized, norm-referenced assessment tool measuring facets of the parent-child system, including child characteristics, parent characteristics, family context, and life stresses (Abidin, 1995). It generates scores on four subscales (total stress; parental distress; parent-child dysfunctional interaction; and, difficult child). It has good psychometric properties including high internal consistency and moderate to high test-retest reliability (Abidin, 1995; Reitman, Currier, & Stickle, 2002). Cutpoints at the 85th percentile of normative data are proposed to indicate severe parenting stress and are labelled “high” in our analysis (Abidin, 1995). Those in Sample 1 completed the PSI-SF at four time points (baseline; midway through program; at the end of the program; and, six months after the program). Those in Sample 2 completed the instrument at baseline and three months later which was approximately the same timing as “midway through the program” for Sample 1.

An interview guide was used to structure the qualitative interviews. It was employed flexibly depending on the knowledge-base of the informant and to explore concepts raised by the informant. A significant focus of the interview was to explore the perceived impacts of the respite program from the informant’s point of view.

Analysis: Initially, paired t-tests were performed to determine whether there were any significant differences in the PSI-SF scales between baseline and midpoint within groups (i.e., intervention group; comparison group; and, qualitative inquiry subgroup). Next, independent t-tests were used to compare baseline to midpoint change scores on the PSI-SF subscales between: (i) intervention versus comparison group; and, (ii) intervention qualitative subgroup versus intervention non-qualitative subgroup. In addition, the total PSI-SF scores from the four data collection points was plotted for the intervention group.

The qualitative interviews were conducted individually via telephone at the end of the respite program year and were audiotaped. Questions were asked in an open-ended manner following interview guides that were adapted as interviewing progressed, based on issues surfacing in initial conversations. Among the questions discussed, parents were asked to describe their experience with the respite program, including their perceived likes/benefits of the program and dislikes/concerns. Interviews were transcribed verbatim and were analyzed by one of the authors using a content analysis approach aimed at identifying themes arising from within the text.
### Table 1. Characteristics of participants in different subgroups

<table>
<thead>
<tr>
<th>Variables</th>
<th>Intervention group (n=35)</th>
<th>Comparison group (n=11)</th>
<th>Qualitative inquiry group (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Parent type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological mother</td>
<td>37.1 (13)</td>
<td>90.9 (10)</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Adoptive mother/other female</td>
<td>25.7 (9)</td>
<td>-</td>
<td>12.5 (1)</td>
</tr>
<tr>
<td>Foster mother</td>
<td>22.9 (8)</td>
<td>-</td>
<td>62.5 (5)</td>
</tr>
<tr>
<td>Biological/adoptive father</td>
<td>11.4 (4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Parent marital status</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/common-law</td>
<td>62.9 (22)</td>
<td>45.5 (5)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td>Single/divorced/separated</td>
<td>37.1 (13)</td>
<td>54.5 (6)</td>
<td>50.0 (4)</td>
</tr>
<tr>
<td>Parent education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>University/college/trades</td>
<td>62.9 (22)</td>
<td>36.3 (4)</td>
<td>75.0 (6)</td>
</tr>
<tr>
<td>High School</td>
<td>22.9 (8)</td>
<td>-</td>
<td>25.0 (2)</td>
</tr>
<tr>
<td>Less than high school</td>
<td>11.4 (4)</td>
<td>54.5 (6)</td>
<td>-</td>
</tr>
<tr>
<td>Index child age (years)</td>
<td>5.5 (1.6)</td>
<td>5.4 (1.7)</td>
<td>6.0 (1.1)</td>
</tr>
</tbody>
</table>

*While there were ten participants in the qualitative study, socio-demographic data on only eight are included here for comparison purposes as only eight had PSI-SF data at baseline and midpoint. Respondent type is missing for one family in the intervention and comparison group.

### Table 2. Parent stress scores and change scores for different subgroups

<table>
<thead>
<tr>
<th>Subscale scores</th>
<th>Intervention group (n=35)</th>
<th>Comparison group (n=11)</th>
<th>Qualitative inquiry group (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD) [% high]</td>
<td>Mean (SD) [% high]</td>
<td>Mean (SD) [% high]</td>
</tr>
<tr>
<td>Total stress score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>102.3 (20.7) [71.4]</td>
<td>109.5 (20.2) [81.8]</td>
<td>100.0 (21.6) [62.5]</td>
</tr>
<tr>
<td>Midpoint</td>
<td>96.9 (20.8) [57.1]</td>
<td>101.0 (17.7) [72.7]</td>
<td>97.9 (22.5) [50.0]</td>
</tr>
<tr>
<td>Change</td>
<td>-5.4 (15.8)</td>
<td>-8.5 (15.4)</td>
<td>-2.1 (17.8)</td>
</tr>
<tr>
<td>Parental distress</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>32.2 (10.2) [37.1]</td>
<td>37.4 (8.1) [63.6]</td>
<td>31.8 (10.8) [50.0]</td>
</tr>
<tr>
<td>Midpoint</td>
<td>28.5 (9.5) [20.0]</td>
<td>35.3 (7.7) [54.5]</td>
<td>28.5 (11.0) [12.5]</td>
</tr>
<tr>
<td>Change</td>
<td>-3.7 (8.7)</td>
<td>-2.2 (5.8)</td>
<td>-3.3 (10.4)</td>
</tr>
<tr>
<td>Parent-child dysfunctional interaction</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>29.5 (7.5) [54.3]</td>
<td>33.1 (9.1) [81.8]</td>
<td>28.6 (9.2) [37.5]</td>
</tr>
<tr>
<td>Midpoint</td>
<td>29.0 (7.3) [62.9]</td>
<td>28.6 (5.9) [45.5]</td>
<td>28.6 (6.8) [37.5]</td>
</tr>
<tr>
<td>Change</td>
<td>-0.5 (5.3)</td>
<td>-4.5 (8.2)</td>
<td>0.0 (4.4)</td>
</tr>
<tr>
<td>Difficult child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baseline</td>
<td>40.6 (8.0) [77.1]</td>
<td>39.1 (8.3) [54.5]</td>
<td>39.6 (5.5) [87.5]</td>
</tr>
<tr>
<td>Midpoint</td>
<td>39.3 (9.1) [57.1]</td>
<td>37.2 (7.1) [63.6]</td>
<td>40.8 (8.7) [62.5]</td>
</tr>
<tr>
<td>Change</td>
<td>-1.2 (7.0)</td>
<td>-1.9 (6.8)</td>
<td>1.1 (7.5)</td>
</tr>
</tbody>
</table>

*No statistically significant pre-post changes (baseline to midpoint) within groups using paired t-tests.  
*No statistically significant change scores between intervention and comparison groups using independent t-tests.  
*No statistically significant change scores between intervention group which participated in qualitative interviews and the group which did not using independent t-tests.  
% high corresponds to cutpoints at the 85th percentile of normative data and suggests severe parenting stress.
Results

Socio-demographic characteristics of the intervention group, comparison group, and qualitative inquiry group (a subset of the intervention group) are summarized in Table 1.

PSI-SF scores for the different groups at baseline and midpoint and extent of change between these two points are summarized in Table 2. No significant differences were found between baseline and midpoint on any of the PSI-SF scales within any of the groups. No significant differences were found in change scores contrasting intervention and comparison group, or between the subgroups in the intervention group (i.e., those who participated in the qualitative inquiry and those who did not).

The total PSI-SF scores for the intervention group at each of the four time points are summarized in Figure 1 demonstrating only small reductions over time.

In contrast to the very modest shifts in values of the PSI-SF, responses within the qualitative inquiry were substantially positive. Participants spoke of the respite program as “immensely beneficial” and “a win, win [situation] for everybody.” Parents had many positive things to say about the impact it had had on themselves, their children, and the rest of their family members.

Four themes related to stress and relief were identified within the qualitative analysis of text derived from the parent interviews: (i) strain reduction; (ii) a gift of time; (iii) increased capacity to handle day to day life; and, (iv) positive emotional impact. Additional analysis of the text explored and identified factors that may have negated, lessened and/or worked contrary to the experience of reduction in parental stress. Supporting text for each of these themes is presented in Table 3.

Discussion

At the group level, there was little to no evidence that the respite program resulted in reduction in stress levels as measured on the PSI-SF. This lack of measurable change for parent stress was similar to the lack of change found on a measure of child mental health status from analysis of the same dataset (Hutcheon, McLennan, & Urichuk, 2011). This lack of demonstrable improvement in child mental health status and the relatively high child mental health difficulty levels perceived by the parents may be a contributing factor to the lack of measurable change in parent stress. The need to link children in respite programs to evidence-based child mental health interventions was flagged in the previous paper and may be an important mechanism for reducing parent stress as well.

While not reporting on stress per se, a meta-analysis of 78 studies for family caregivers of older adults found statistically significant improvements in related measures of caregiver burden, depression, and subjective well-being (Sörensen, Pinquart, & Duberstein, 2002). While we were not able to identify a meta-analytic examination of respite care for children, individual studies have found significant quantitative changes in parent stress (Chan & Sigafoos, 2001; Strunk, 2010). However, this cannot be extended to presume that all or
even most respite services are achieving this goal. There may even be a potential for some programs to increase stress. One pilot study of caregivers of adults with mental illness reported that those who received a respite intervention reported an increase in stress compared to those not receiving the service (Jardim & Pakenham, 2009).

Despite the lack of quantifiable improvements in parent stress, a subgroup of parents’ articulated substantial benefits, several that presumably are related to stress. Another study found a similar split between the qualitative and quantitative findings from a family intervention. Kalek (2009) reported very positive feedback as captured in narratives from parents about an early intervention program, however, minimal changes in parent stress were found.

It is proposed that the respite program under study may have provided a temporary break giving a sense of relief but did not impact on more chronic stress patterns and that these are related but separate constructs and experiences. Though the respite time was substantial (over 200 hours in 10 months), it represents only a fraction of care-giving time of the parents. Additional or different interventions are likely needed if the intent is to lower chronic stress levels of parents with special needs children.
There are a number of limitations to this study. The sample size for the quantitative analysis was relatively small which reduced the power to detect smaller differences. In addition, the nature of the sample may also have implications. This includes a relatively high percentage of the participants having more than high school education suggesting that the participants may not represent the typical distribution of families accessing respite care. In addition, there was a diversity of parent types and combining these different types may have limitations given potential differences in parent characteristics, experiences, and contexts (e.g., Dolan, Casanueva, Smith, & Bradley, 2009; Daniel, 2011). Given the small sample size it was not possible to analyze the data separately by parent type.

There may also be concerns about the comparison sample given the non-randomized nature of group assignment. However, were the positions not filled in the intervention program, these families could have been participants, i.e., they would have met the inclusion criteria for the intervention program. As well, the attempt to include some comparison sample in program evaluation is important to look at the potential “natural course” for families not getting the intervention in question, in this study a specific intensive respite program. In particular, if the “natural course” is one
of deterioration, then a finding that the intervention group, while not improving, did not deteriorate may actually be a positive finding. This did not appear to be the case in this study based on the small comparison sample. While it could be argued that the respite services received by the comparison group was also effective in preventing deterioration, this then raises the question as to whether a less intensive and expensive intervention may be similarly effective as the centre-based program, however, a rigorous cost-effectiveness study would be required to determine this.

There may also be limitations to the qualitative component of the study. The sample was selected purposively to capture a diversity of perspectives and was not aimed at obtaining a representative sample. In addition, there may be a bias towards parents reporting positive experiences with the receipt of social and health services, particularly with more direct approaches with personal contact (Garratt, Bjertnaes, Holmboe, & Hanssen-Bauer, 2011). This may have been exacerbated in this study given some evidence of a social desirability bias reporting with telephone interviews versus survey (Bjertnaes, Iversen, & Bukhom, 2010). In attempt to mitigate this bias, the researcher staff members were quite distinct from the provider staff and emphasis was placed on the anonymity of responses and the request to describe any positive or negative experiences with the service. An additional limitation is that only one author coded the qualitative text and therefore inter-rater agreement on coding was not conducted.

Finally, this study only considered the evaluation of one-respite program and generalizability to other respite programs is unknown.

Despite these limitations, the study flags the need for further evaluation of respite services. There are still many unanswered questions as to what types of respite services work best for whom, for what problems, and to what effect. Building in rigorous evaluation within real-world services is essential if there is an interest and aim to optimize the impact of health and social services. Thoughtful use of mixed-method designs incorporating quantitative and qualitative components should be considered given the potential for complementary information derived from these different approaches. An aim should be that interventions that demonstrate meaningful gains as captured by both quantitative and qualitative means receive priority funding.

Acknowledgments / Conflicts of Interest

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References


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