

BRIEF REPORT: Knowledge as Coping in Parents of Children with Autism

Abstract

The purpose of this study was to explore knowledge as a possible factor influencing the positive and negative outcomes of parents of children with autism. A sample of 94 families was included in this study. Child severity data was collected using file review, and the parents completed a brief questionnaire about parenting stress, positive impact, actual knowledge about autism and intensive behavioural intervention, and perceived knowledge. A moderate positive correlation was found between actual and perceived knowledge. In addition, perceived knowledge (but not actual knowledge) was a significant predictor of positive impact, but not negative impact.

When raising a child with a pervasive disorder such as autism, parents may experience both negative (e.g., stress) and positive (e.g., increased self confidence/efficacy) impacts. Research suggests that these outcomes may vary across parents and points in time depending on various child (e.g., behaviour problems, IQ, and adaptive levels), family and personal factors (Blacher & Baker, 2007; McCubbin & Patterson, 1983; Weiss, Sullivan & Diamond, 2003). According to Perry (2004), these outcomes are not mutually exclusive, and they can coexist. Negative outcome may be ameliorated or positive outcome can be enhanced by various intervening factors such as parent personality and coping style, social and familial resources, as well as formal supports and services.

One means of coping used by parents is seeking out information and training in order to become knowledgeable about their child's disorder and relevant treatment. In a recent study, Solish and Perry (2011) found a positive correlation between parents' perceived knowledge about autism and Intensive behaviour Intervention (IBI) and their self-efficacy. This suggests that the perception of having sufficient knowledge to help their child may act as a positive force in the overall outcome for parents. However, there is variability in the level of actual and perceived knowledge across parents based on several factors such as beliefs and culture (Luthra & Perry, 2011). In addition, we do not know what the relationship is between actual and perceived knowledge, nor which one is more strongly related to coping and parent outcomes. The purpose of this study was to explore three main questions: (a) What is the relationship between actual and perceived knowledge, (b) What is the relationship between the dependent variables (parenting stress and positive impact) and the independent variables (child severity, actual knowledge and perceived knowledge), (c) Does actual or perceived knowledge account for significant variance in negative or positive outcomes?

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Table 1. Mean and Standard Deviation of all the Variables

	<i>Minimum</i>	<i>Maximum</i>	<i>M (SD)</i>	
Child Severity	2	9	5.13	(1.60)
Actual Knowledge	1	10	8.01	(1.40)
Perceived Knowledge	2	9	8.55	(1.65)
Negative Impact	12	58	32.59	(11.05)
Positive Impact	45	90	65.89	(11.12)

Method

Participants

A secondary data analysis was done using a sample of 94 families of children with autism across Ontario from other studies (Solish & Perry, 2008, 2011; Luthra & Perry, 2011), who provided consent for using their information for future research. Based on our classifications of scores from the Barratt Simplified Measure of Social Status (Barratt, 2006), 41% of the families fell in the low socio-economic status (SES), 33% in the medium and 26% in the high SES brackets. The children were 77 males and 17 females, with an average age of 6 years, 3 months.

Measures

The Child Severity scores were constructed using a Developmental Severity rating of 1 (high) to 5 (low) based on their IQ and/or adaptive scores (Vineland II; Sparrow, Cicchetti, & Balla, 2005) on standardized tests and a Diagnostic Severity rating of 1 (low) to 5 (high) based on their score on the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988). The sum of these two ratings resulted in the child Severity score, with a possible range from 2 to 10.

In addition, the parents had completed the Parent Involvement Questionnaire (Solish & Perry, 2008) which included 20 True-False items measuring their Actual Knowledge about Autism and IBI, two 5-point Likert type questions about their Perceived Knowledge (perception of their knowledge compared to the general population), as well as positive and

negative outcomes. Negative outcome was measured using 12 items from the Parenting Stress Index-Short Form, Parental Distress Domain (PSI-SF, PD domain; Abidin, 1995) and positive outcome using 18 items from the Parental Change Subscale (Scorgie & Sobsie, 2000). The mean and standard deviation of the scores in the sample are shown in Table 1.

Data Analysis

Data were analyzed using Pearson product-moment correlations between all variables and hierarchical linear regressions (Tabachnik & Fidell, 2007) for identifying predictors of parent outcomes, using SPSS version 16.

Results

Correlations among all variables are shown in Table 2. A moderate significant correlation ($r = .44$) was present between actual and perceived knowledge. In addition, there was a significant correlation between perceived knowledge and positive impact on parents ($r = .21$). All other correlations between dependent and independent variables were not significant.

Two hierarchical regressions (Tabachnik & Fidell, 2007) were conducted in order to test how much variance in parenting stress and positive impact can be attributed to actual and perceived knowledge, when child severity was held constant. The results suggest that actual or perceived knowledge contributed very little to the variance in parenting stress. However, perceived knowledge was a significant predictor of positive impact ($\beta = .28, p < .05$) contributing 7.3% of the variance.

Table 2. Correlations among all the Dependent and Independent Variables

	Child Severity	Actual Knowledge	Perceived Knowledge	Negative Impact	Positive Impact
Child Severity		.02	.02	.12	.08
Actual Knowledge			.44*	-.01	-.04
Perceived Knowledge				-.08	.21*
Negative Impact					-.54*
Positive Impact					

* $p < .01$.

Discussion

This study was conducted in order to improve our understanding about the role of parent knowledge and training on parent outcomes and to add to the limited research in this area. In this study, actual and perceived knowledge were moderately correlated with each other which suggests that most parents who thought they knew more did have significantly higher knowledge than those who reported knowing less.

There are opposing views in the literature about how child factors influence parenting stress and positive impact. The hierarchical regression conducted in this study suggests that child severity (at least the way we measured it in this study) was not predictive of either negative or positive outcomes. This may imply that parents' level of stress is independent of how difficult the child is, or perhaps there are other intervening factors that influence these two outcomes (Perry, 2004).

In terms of knowledge as a predictor or correlate of positive or negative outcomes, we found that, when child severity is kept constant parents' actual knowledge was not predictive. Perceived knowledge did not predict negative outcomes, but it was significantly correlated with positive impact and in the regression accounted for 7.3% of the variance.

Moreover, it may be true that actual knowledge does not necessarily influence parent outcomes directly, but is significantly correlated with their perception of how much they know, which in turn is related to increased positive outcomes. Therefore, perceived knowledge is likely a combination of actual knowledge as well as self-confidence about their level of knowledge,

which may act as a form of secondary appraisal or coping. These results suggest that there is a need for improved parent education and training to help improve their sense of self efficacy and confidence in helping their child.

Some limitations of this study are that the sample was not big enough to conduct a moderator analysis, and some of the child data was missing. Future research could study perceived knowledge in comparison or relation to other coping strategies.

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Key Messages from the Article

People with disabilities: The severity of disability in a child does not necessarily predict negative outcomes in parents.

Professionals: There is a need to look beyond the immediate presenting problems in the child, and promote greater knowledge and self confidence in parents of children with disabilities such as autism. This may not necessarily reduce the daily stressors that parents experience, but may help promote positive experiences.

Policy makers: Family counselling and parent training programs may need to be developed as an essential part of family services for children with disabilities such as autism.

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